Brief Report

Perceptions of people with intellectual and developmental disabilities about COVID-19 in Spain: a cross-sectional study

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Abstract

Background As the world battles COVID-19, there is a need to study the perceptions of people with intellectual and developmental disabilities (IDD) about the effects of the pandemic and associated lockdown on their lives. This work explores the perceptions of Spaniards with IDD during the lockdown with respect to four topics: access to information, emotional experiences, effects on living conditions and access to support.

Methods The topics were explored using a subset of 16 closed-ended questions from an online survey. In total, 582 participants with IDD completed the survey. The frequencies and percentages of responses to the questions were calculated, and chi-square tests performed to explore the relationship between participants' sociodemographic characteristics and responses. Given that people differed in the way in which they completed the survey, the relationship between participants' responses and completion method was also analysed.

Results Participants reported that the pandemic and subsequent lockdown have had a deleterious effect on their emotional well-being (around 60.0% of participants) and occupations (48.0% of students and 72.7% of workers). Although access to information and support was reportedly good overall, being under the age of 21 years and studying were associated with perceptions reflecting poorer access to information ($V^2 = .20$ and $V^2 = .13$, respectively) and well-being support ($V^2 = .15$ and $V^2 = .13$, respectively). Being supported by a third party to complete the survey was consistently related to perceptions of worse outcomes.

Conclusions The study yielded data on the perceptions of people with IDD regarding the effects that COVID-19 and the subsequent lockdown have had on their lives. Suggestions on how to overcome the difficulties reported and future lines of research are discussed.

Keywords COVID-19, developmental disability, intellectual disability, lockdown, perceptions, survey

Since the start of the COVID-19 crisis, organisations, families and researchers worldwide have been concerned about the risks for people with intellectual
and developmental disabilities (IDD). Several international studies have highlighted the vulnerability of people with IDD in terms of their health, inclusion and rights arising from the COVID-19 pandemic and measures implemented to ‘flatten the curve’ (e.g. Courtenay & Perera 2020), and guidelines have been developed on how to provide support during this crisis (e.g. Alexander et al. 2020). However, few studies have explored how this situation has directly affected people with IDD, with the majority focusing on carers’ perceptions (e.g. Neece et al. 2020). Indeed, in the review conducted for this article (search terms, language, databases, period and records are available on request), only two of 205 works on COVID-19 and IDD included people with IDD as direct participants (Drum et al. 2020; Embregts et al. 2020). In a survey distributed to 930 adults with IDD in the USA, Drum et al. (2020) found that 20% of participants who suffered anxiety and depression were unable to access emotional support, 25% stopped receiving direct care services, more than half experienced disruptions in their regular healthcare treatment services and 38% experienced difficulties accessing health care. In the other study, conducted by Embregts et al. (2020) on six people with IDD in the Netherlands, their main concerns were found to be the need for social contact, the changes to daily life posed by the lockdown and difficulties in understanding preventive measures.

The current international state of the art with respect to COVID-19 and people with IDD reveals two critical needs: (1) to give people with IDD a voice to express their needs and experiences with respect to the pandemic and (2) to further explore pressing lines of research that have been highlighted in the literature. Among these questions is the need to examine whether people with IDD have been provided with access to COVID-19 resources to promote their rights to health and information [European Association of Service Providers for Persons with Disabilities (EASPD) 2020; United Nations 2020]. Moreover, research into the emotional experiences of people with IDD during the pandemic is necessary given the higher prevalence of mental health conditions among this group (Emerson et al. 2010; Hughes-McCormack et al. 2017), meaning that they may face greater difficulties compared with the general population. Finally, the literature highlights the need to understand the effects of COVID-19 on people with IDD in terms of their living conditions and access to support. This is because the lockdown – along with the lack of social service planning by authorities – may have resulted in this group not receiving the support and services necessary for inclusion in their communities (EASPD 2020; Hughes & Anderson 2020).

The COVID-19 situation in Spain is similar to that found in other countries, including the policies adopted and measures implemented to fight the virus. For example, as in many other European countries (EASPD 2020), people with IDD and their families have suffered from a lack of social service planning by authorities and the adoption of measures that have been insensitive to their needs (Galván 2020). Research in Spain on the effects of the pandemic and lockdown on the lives of people with IDD has remained stagnant in comparison with international studies. In fact, none of the 205 works mentioned earlier have explored how the situation has affected Spaniards with IDD from their own perspectives or those of their relatives. Given that Spain has been one of the countries most affected by COVID-19, this lack of research is especially troubling.

Thus, the present study explores the perceptions of Spanish people with IDD on the effects of COVID-19 and the subsequent lockdown (14 March to 21 June 2020) on their lives. Further, this study explores the needs of people with IDD regarding the topics considered a priority by the Spanish Committee on Representatives of Persons with Disabilities (2020) and the international literature (e.g. Courtenay & Perera 2020; Embregts et al. 2020; Hughes & Anderson 2020): (1) access to information, (2) emotional experiences, (3) effects of COVID-19 and the subsequent lockdown on living conditions and (4) access to support to cope with the situation.

**Methods**

**Participants**

Participants were selected using incidental sampling. As stated in the survey’s information section, participants were required to have at least a diagnosed intellectual disability. According to Cochran’s (1977) formula to determine sample size, 385 participants were needed to represent the Spanish population living with IDD, currently totalling $N = 274,883$. 

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A total of 1347 participants accessed the survey, 644 (46.9%) of whom completed it in full. Sixty-two surveys were duplicate responses and thus were eliminated, resulting in 582 completed surveys by people with IDD from all Spanish regions. The average age of participants was 35.6 years (standard deviation = 14.1, range = 3–83 years). The number of completed responses yielded a sampling error of 4%, which was below the 5% level commonly accepted in survey-based research (e.g. Khodaparast & Hassani 2015; Okafor & Goon 2020).

Approximately two-thirds of participants answered the survey directly, either independently (n = 238, 40.9%) or supported by another person (n = 135, 23.2%). The remaining surveys (n = 209, 35.9%) were completed by relatives or professionals, who used the survey questions to interview participants with IDD and collect information about the participants’ lived experiences. Table 1 summarises the participants’ sociodemographic characteristics.

**Instrument**

The questions analysed in this study are part of an online survey designed by the research team using the following sources: (1) a literature review on COVID-19 and its effects on the living conditions of people with disabilities, (2) reports by international organisations on the risks posed by the pandemic for people with IDD, (3) institutional repositories on COVID-19 and (4) Schalock and Verdugo’s (2002) quality of life model.

An initial set of questions was developed and shared with seven IDD experts from the fields of psychology, sociology, medicine and law, who discussed the questions with the authors of the present study to develop a preliminary version of the survey. The preliminary survey was sent to the family task group at Plena inclusión. Plena inclusión is the main service provider for people with IDD in Spain and comprises 935 organisations. The family task group, consisting of 22 professionals and family representatives from all Spanish regions, studied the questions and proposed the following modifications: (1) to include an option for people who were both studying and working (rather than just studying or working), (2) to present only the questions relevant to each respondent depending on their previous answers and (3) to change the survey to an interview when it was not possible for the participant to answer it directly (e.g. people with higher support needs). All suggestions were incorporated by the research team. The resultant survey was validated as easy to read by both an expert in cognitive accessibility and a person with IDD.

The final survey included 41 closed-ended and seven open-ended questions to gain a deeper understanding of the former. Following a discussion on the relevance of each question to the research needs identified by international research and the Spanish Committee on Representatives of Persons with Disabilities (2020), the authors discretionally selected the questions to be analysed. Table 2 shows the 16 closed-ended questions analysed and the topics they addressed. Readers can access the complete survey in the following link: https://inico.usal.es/wp-content/uploads/2020/09/Encuesta-para-personas-con-discapacidad-intelectual-y-del-desarrollo.pdf.

**Procedure**

Using the Plena inclusión network, the survey was sent by email to its 935 organisations with a request to disseminate it among people with IDD. To reach participants who were supported by other service

| Variable                  | N   | %    |
|---------------------------|-----|------|
| Gender                    |     |      |
| Male                      | 279 | 47.9 |
| Female                    | 303 | 52.1 |
| Total                     | 582 | 100  |
| Age group                 |     |      |
| Up to 21 years old        | 84  | 14.4 |
| Between 22 and 44 years old | 344 | 59.1 |
| 45 years old or older     | 154 | 26.5 |
| Total                     | 582 | 100  |
| Housing type              |     |      |
| Family/own home           | 464 | 79.7 |
| Disability-related services | 106 | 18.2 |
| Another place             | 12  | 2.1  |
| Total                     | 582 | 100  |
| Occupation                |     |      |
| Study                     | 135 | 23.2 |
| Work                      | 195 | 33.5 |
| Study and work            | 42  | 7.2  |
| Neither work nor study    | 210 | 36.1 |
| Total                     | 582 | 100  |
Table 2. Survey’s questions selected to examine the research topics

| Survey’s closed-ended questions selected and response options | Topic addressed |
|-------------------------------------------------------------|-----------------|
| 1. Did you receive information on COVID-19? | Access to information |
| ( ) Yes () No | |
| 2. Was this information easy for you to understand? (only for those who answered ‘Yes’ to the previous question) | |
| ( ) Yes () No | |
| 3. Did you understand why the government has decided that we cannot go out? | |
| ( ) Yes () No | |
| 4. Have you been frightened these days because of COVID-19? | Emotional experiences during the lockdown |
| ( ) Yes () No | |
| 5. Have you been more nervous than usual these days because of COVID-19? | |
| ( ) Yes () No | |
| 6. Have you changed the place where you live since COVID-19 and the lockdown started? | Effects on living conditions |
| ( ) Yes () No | |
| 7. Where have you been living since this crisis started? | |
| ( ) In a service dependent on my organisation (e.g. a residence or in a flat) | |
| ( ) With my family or on my own | |
| ( ) In another place | |
| 8. Can you study remotely without difficulties? (only for students) | |
| ( ) Yes () No | |
| 9. Can you tell us the problems you have with studying remotely? (only for those who answered ‘No’ to the previous question) | |
| ( ) Difficulties in understanding the teacher’s explanations | |
| ( ) Difficulties in understanding the tasks | |
| ( ) I don’t have internet or a computer to study remotely | |
| ( ) I cannot concentrate well, or I am not motivated | |
| ( ) I miss someone who helps me study and complete my homework | |
| ( ) I have problems with using the computer for studying | |
| 10. Have you been able to continue working without difficulties? (only for workers) | |
| ( ) Yes () No | |
| 11. Can you tell us the difficulties you have with continuing to work? (only for those who answered ‘No’ to the previous question) | |
| ( ) I do the same job, but with protection measures | |
| ( ) I have to work remotely | |
| ( ) I have been sent home and I receive money | |
| ( ) I have been sent home and I do not receive any money | |
| ( ) I am on sick leave | |
| 12. Are you receiving help or support to face the lockdown? | Access to support to face the crisis |
| ( ) Yes () No | |
| 13. Do you miss someone or are you missing something to help you face this situation better? | |
| ( ) Yes () No | |
| 14. Are you receiving help or support to study remotely? (only for students) | |
| ( ) Yes () No | |
| 15. Who helps you study remotely? (only for those who answered ‘Yes’ to the previous question) | |
| ( ) My disability organisation | |
| ( ) My family helps me | |
| ( ) My classmates | |
| ( ) The teacher | |
| 16. Have you missed support to help you maintain your well-being? Please note that when we say well-being, we refer to a state in which you feel secure and satisfied with your life | |
| ( ) Yes () No | |
providers, the online survey was also disseminated via the Plena Inclusion and Institute for Community Inclusion websites and social media using easy-to-read instructions. This strategy was complemented with an email distribution list to all organisations that had collaborated with the research team in previous investigations, with more than 1000 emails sent in total. Given the possibility of the survey being implemented as an interview by a relative or carer, instructions accompanying the survey stated that interviewers should not reflect their own perceptions but those of the participants being interviewed.

The survey was created using the Lime Survey platform. Along with general and question-specific instructions, the survey incorporated visual prompts to help participants answer the questions. The survey was hosted on the University of Salamanca’s server to maximise data privacy and security (only the members of the research team could access the data). Participants could save their answers to avoid having to complete the survey in one attempt. The survey took around 20 min to complete, as reported by the person with IDD who helped to validate the survey in an easy-to-read format.

Data collection occurred from 1 June to 30 June 2020. The work complied with the Declaration of Helsinki (World Medical Association 2013) and the General Data Protection Regulation [Regulation (EU) 2016/679] and received the approval of an ethics committee external to Plena Inclusion.

**Data analysis**

A cross-sectional study was conducted, and the frequencies and distribution of responses were analysed. To better understand the effects of the pandemic and lockdown from the perspectives of individuals with IDD, the statistical dependence between participants’ sociodemographic variables and their answers was analysed. Given that one-third of the participants had to be interviewed, the relationships between the completion method (i.e. direct vs. indirect) and participants’ responses were also analysed.

To study these relationships, chi-square tests of independence were performed alongside Cramer’s $V$ to measure effect size: $V > .25$ = very strong effect, $V > .15$ = strong effect, $V > .10$ = moderate effect, $V > .05$ = weak effect and $V < .05$ = negligible effect (Akoglu 2018). For questions conditional on participants’ previous answers (i.e. 7, 9, 11 and 15 in Table 2), only frequencies and percentages were reported because of the small sample size and high number of response options (i.e. cells with counts <5). Data were analysed using SPSS v. 25 ($\alpha = .05$).

**Results**

Participants’ responses and their relationship with their sociodemographic characteristics are reported first, followed by the relationship between completion method and responses.

**Access to information**

Most participants ($n = 521, 89.5\%$) reported having received information about COVID-19, and 422 of these participants (81.0\%) found it easy to understand. Whether or not participants received information was unrelated to their sociodemographic characteristics. Perceiving that they understood the information about COVID-19 was strongly related to age [$\chi^{2} (2, N = 521) = 20.6, p < .001; V = .20$] and moderately related to occupation [$\chi^{2} (3, N = 521) = 8.9, p = .031; V = .13$]. Those younger than 21 years of age (38.6\%) and students (27.2\%) found it difficult to understand COVID-19 information.

Most participants ($n = 507, 87.1\%$) stated that they understood the purpose of the lockdown. Age [$\chi^{2} (2, N = 582) = 12.9, p = .002$] and occupation [$\chi^{2} (3, N = 582) = 13.7, p = .003$] were moderately ($V = .15$) related to perceiving understanding the reason for the lockdown, with those under 21 years of age (25.0\%) and those not working or studying (16.7\%) reporting greater difficulty in understanding it. Table 3 summarises all the relationships between participants’ sociodemographic characteristics and their answers to the questions addressing this topic.

**Emotional experiences during the lockdown**

Almost 60\% of participants reported feeling afraid ($n = 348$) or more anxious ($n = 347$) because of the virus and subsequent lockdown. Although the association between variables was weak ($V = .09$), women were more likely to feel afraid [$\chi^{2} (1, N = 582) = 4.7, p = .030$, odds ratio = 1.45] or anxious [$\chi^{2} (1, N = 582) = 4.4, p = .037$, $V = .09$, odds
Table 3. Relationship between participants’ sociodemographic characteristics and their answers to the questions addressing ‘access to information’

| Variable | N Yes (%) | N No (%) | \(\chi^2\) | p   | V   |
|----------|-----------|----------|-----------|------|-----|
| **Question 1: Did you receive information on COVID-19?** | | | | | |
| Total answers (n = 582) | 521 (89.5) | 61 (10.5) | | | |
| Gender | | | | | |
| Male (n = 279) | 247 (88.5) | 32 (11.5) | 0.56 | .45 | .03 |
| Female (n = 303) | 274 (90.4) | 29 (9.6) | | | |
| Age group | | | | | |
| Up to 21 years old (n = 84) | 70 (83.3) | 14 (16.7) | 4.6 | .098 | .09 |
| Between 22 and 44 years old (n = 344) | 309 (89.8) | 35 (10.2) | | | |
| 45 years old or more (n = 154) | 142 (92.2) | 12 (7.8) | | | |
| Housing type | | | | | |
| Family/own home (n = 464) | 409 (88.1) | 55 (11.9) | 4.7 | .093 | .09 |
| Disability-related services (n = 106) | 101 (95.3) | 5 (4.7) | | | |
| Another place (n = 12) | 11 (91.7) | 1 (8.3) | | | |
| Occupation | | | | | |
| Study (n = 135) | 114 (84.4) | 21 (15.6) | 5.0 | .170 | .09 |
| Work (n = 195) | 179 (91.8) | 16 (8.2) | | | |
| Study and work (n = 42) | 38 (90.5) | 4 (9.5) | | | |
| Neither work nor study (n = 210) | 190 (90.5) | 20 (9.5) | | | |
| **Question 2: Was this information easy for you to understand?** | | | | | |
| Total answers (n = 521) | 422 (81.0) | 99 (19.0) | | | |
| Gender | | | | | |
| Male (n = 247) | 203 (82.2) | 44 (17.8) | 0.43 | .512 | .03 |
| Female (n = 274) | 219 (79.9) | 55 (20.1) | | | |
| Age group | | | | | |
| Up to 21 years old (n = 70) | 326 (75.0) | 27 (38.6) | 20.6 | <.001 | .20 |
| Between 22 and 44 years old (n = 309) | 257 (83.2) | 52 (16.8) | | | |
| 45 years old or more (n = 142) | 122 (85.9) | 20 (14.1) | | | |
| Housing type | | | | | |
| Family/own home (n = 409) | 326 (79.7) | 83 (20.3) | 2.2 | .336 | .06 |
| Disability-related services (n = 101) | 87 (86.1) | 14 (13.9) | | | |
| Another place (n = 11) | 9 (81.8) | 2 (18.2) | | | |
| Occupation | | | | | |
| Study (n = 114) | 154 (86.0) | 31 (27.2) | 8.9 | .031 | .13 |
| Work (n = 179) | 152 (80.0) | 25 (14.0) | | | |
| Study and work (n = 38) | 33 (86.8) | 5 (13.2) | | | |
| Neither work nor study (n = 190) | 152 (80.0) | 38 (20.0) | | | |
| **Question 3: Did you understand why the government has decided that we cannot go out?** | | | | | |
| Total answers (n = 582) | 507 (87.1) | 75 (12.9) | | | |
| Gender | | | | | |
| Male (n = 279) | 241 (86.4) | 38 (13.6) | 0.26 | .612 | .02 |
| Female (n = 303) | 266 (87.8) | 37 (12.2) | | | |
| Age group | | | | | |
| Up to 21 years old (n = 84) | 63 (75.0) | 21 (25.0) | 12.9 | .002 | .15 |
| Between 22 and 44 years old (n = 344) | 306 (89.0) | 38 (11.0) | | | |
| 45 years old or more (n = 154) | 138 (89.6) | 16 (10.4) | | | |
| Housing type | | | | | |
| Family/own home (n = 464) | 398 (85.8) | 66 (14.2) | 3.6 | .161 | .08 |
| Disability-related services (n = 106) | 98 (92.5) | 8 (7.5) | | | |
| Another place (n = 12) | 11 (91.7) | 1 (8.3) | | | |
| Occupation | | | | | |
| Study (n = 135) | 111 (82.2) | 24 (17.8) | 13.7 | .003 | .15 |
ratio = 1.42]. Being more anxious was also associated with the living context \( \chi^2 (2, N = 582) = 7.3, p = .026, V = .11 \), with those living in disability-related services being more anxious than usual (65.1%). No significant associations were found between these emotions and any other sociodemographic variables. Complete information on the responses provided by participants to this topic according to their sociodemographic characteristics can be found in Table 4.

Effects of COVID-19 and lockdown on participants’ living conditions

Only 57 (9.8%) participants had to change their housing location during the lockdown, and this was strongly related to their initial living context \( \chi^2 (2, N = 582) = 18.9, p < .001, V = .18 \). A high and significant proportion of people who were living in disability-related services changed their living context \( (n = 21, 19.8\%) \). These were mainly adults over the age of 22 years \( (n = 20, 95.2\%) \), and the most common change was moving from disability-related services into the family home \( (n = 10) \).

With regard to the effects of COVID-19 and the lockdown on occupation, among the participants who were studying and answered this question \( (n = 171; 96.6\%) \), 52.0% \( (n = 89) \) reported no difficulties adapting to online education. Although there was no significant association between reporting such difficulties and any sociodemographic characteristics, age was moderately related \( \chi^2 (2, N = 171) = 4.0, p = .135, V = .15 \), with those under 21 years of age reporting difficulties to study remotely in a higher proportion than did adults above 22 years \( (57.4\% \text{ vs. } 41.9\%) \). Students who were unable to follow online education \( (n = 82, 48.0\%) \) stated that they had difficulty with understanding teachers’ explanations and tasks \( (n = 50, 61.0\%) \), attention/concentration \( (n = 6, 7.3\%) \) or interacting with the virtual environment \( (n = 6, 7.3\%) \) or experienced a lack of support \( (n = 6, 7.3\%) \). Among employed participants \( (n = 237) \), the majority \( (n = 168, 72.7\%) \) indicated they had been unable to continue working in the same way, regardless of their sociodemographic characteristics. Among the difficulties reported, 115 \( (68.3\%) \) suffered an interruption of their work, 20 \( (11.9\%) \) continued their work but with restrictive measures, 19 \( (11.3\%) \) had to adapt to working remotely and 7 \( (4.2\%) \) experienced temporary layoffs. Table 5 shows participants’ answers to these questions by sociodemographic characteristics.

Access to support to face the crisis

Most participants \( (n = 478, 82.1\%) \) reported receiving assistance with managing the lockdown. Although the majority claimed that they had received support, 330 \( (91.1\%) \) expressed that they missed someone or something during lockdown. These responses were unrelated to any sociodemographic characteristics.

Twenty-two per cent \( (n = 128) \) of participants reported a lack of support to maintain their well-being during the lockdown. This was strongly related to age \( \chi^2 (2, N = 582) = 13.6, p = .001, V = .15 \) and moderately related to previous occupation \( \chi^2 (3, N = 582) = 9.5, p = .024, V = .13 \). A high and significant proportion of those under the age of 21 years \( (36.9\%) \) and students \( (30.4\%) \) reported a lack of this type of support.

Seventy-three students \( (42.7\%) \) claimed that they had not received support for online education, which was strongly related to age \( \chi^2 (2, N = 171) = 28.8, p < .001, V = .41 \). Individuals under the age of 21 years received more support \( (79.4\%) \) than did adults \( (38.7\%) \). Educational support was mostly

Table 3. (Continued)

| Variable                           | N No (%) | N Yes (%) | \( \chi^2 \) | p    | V   |
|-----------------------------------|---------|-----------|-------------|------|-----|
| Work \( (n = 195) \)              | 14 (7.2)| 181 (92.8)|            |      |     |
| Study and work \( (n = 42) \)     | 2 (4.8 )| 40 (95.2 )|            |      |     |
| Neither work nor study \( n = 210 \) | 35 (16.7)| 175 (83.3)|            |      |     |

Percentages in bold indicate the level of the variable for which the standardised residual exceeded ±1.96 z scores, indicating that the existing relationship occurred for that response category.
provided by relatives \((n = 81, 82.7\%)\), while little support was provided by organisations \((n = 9, 9.4\%)\) or school communities \((n = 4, 4.8\%)\). Detailed results for this research topic can be found in Table 6.

### Relationships between participants’ responses and completion method

Being supported by a third party to complete the survey \(i.e.\) indirectly completion via interviews) was consistently related to perceptions reflecting poorer outcomes, as shown in Table 7.

### Discussion

This study yielded cross-sectional data on the perceptions of 582 people with IDD during the lockdown in Spain with respect to four topics highlighted as critical by international research \(e.g.\) Courtenay & Perera 2020; Embregts \textit{et al.} 2020; Hughes & Anderson 2020) and global \(EASPD 2020;\)

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#### Table 4  Distribution of participants’ responses by sociodemographic characteristics to questions exploring their ‘emotional experiences’

| Variable | \(N\) No (%) | \(N\) Yes (%) | \(\chi^2\) | \(p\) | \(V\) |
|----------|---------------|---------------|-----------|-------|------|
| **Question 4: Have you been frightened these days because of COVID-19?** | | | | | |
| Total answers \((n = 582)\) | 234 (40.2) | 348 (59.8) | | | |
| Gender | | | | | |
| Male \((n = 279)\) | 125 (44.8) | 154 (55.2) | 4.7 | .030 | .09 |
| Female \((n = 303)\) | 109 (36.0) | 194 (64.0) | | | |
| Age group | | | | | |
| Up to 21 years old \((n = 84)\) | 42 (50.0) | 42 (50.0) | 5.1 | .076 | .09 |
| Between 22 and 44 years old \((n = 344)\) | 127 (36.9) | 217 (63.1) | | | |
| 45 years old or more \((n = 154)\) | 65 (42.2) | 89 (57.8) | | | |
| Housing type | | | | | |
| Family/own home \((n = 464)\) | 186 (40.1) | 278 (59.9) | 0.02 | .990 | .01 |
| Disability-related services \((n = 106)\) | 43 (40.6) | 63 (59.4) | | | |
| ’Another place’ \((n = 12)\) | 5 (41.7) | 7 (58.3) | | | |
| Occupation | | | | | |
| Study \((n = 135)\) | 47 (34.8) | 88 (65.2) | 4.6 | .203 | .09 |
| Work \((n = 195)\) | 86 (44.1) | 109 (55.9) | | | |
| Study and work \((n = 42)\) | 13 (31.0) | 29 (69.0) | | | |
| Neither work nor study \((n = 210)\) | 88 (41.9) | 122 (58.1) | | | |
| **Question 5: Have you been more nervous than usual these days because of COVID-19?** | | | | | |
| Total answers \((n = 582)\) | 235 (40.4) | 347 (59.6) | | | |
| Gender | | | | | |
| Male \((n = 279)\) | 125 (44.8) | 154 (55.2) | 4.4 | .037 | .09 |
| Female \((n = 303)\) | 110 (36.3) | 193 (63.7) | | | |
| Age group | | | | | |
| Up to 21 years old \((n = 84)\) | 36 (42.9) | 48 (57.1) | 0.33 | .846 | .02 |
| Between 22 and 44 years old \((n = 344)\) | 136 (39.5) | 208 (60.5) | | | |
| 45 years old or more \((n = 154)\) | 63 (40.9) | 91 (59.1) | | | |
| Housing type | | | | | |
| Family/own home \((n = 464)\) | 197 (42.5) | 267 (57.5) | 7.3 | .026 | .11 |
| Disability-related services \((n = 106)\) | 37 (34.9) | 69 (65.1) | | | |
| ’Another place’ \((n = 12)\) | 1 (8.3) | 11 (91.7) | | | |
| Occupation | | | | | |
| Study \((n = 135)\) | 49 (36.3) | 86 (63.7) | 2.2 | .540 | .06 |
| Work \((n = 195)\) | 86 (44.1) | 109 (55.9) | | | |
| Study and work \((n = 42)\) | 16 (38.1) | 26 (61.9) | | | |
| Neither work nor study \((n = 210)\) | 84 (40.0) | 126 (60.0) | | | |

Percentages in bold indicate the level of the variable for which the standardised residual exceeded \(\pm 1.96\) \(z\) scores, indicating that the existing relationship occurred for that response category.
Table 5  Participants’ perceptions about the ‘effects of the pandemic on their living conditions’ according to their sociodemographic characteristics

| Variable | N No (%) | N Yes (%) | \( \chi^2 \) | p | V |
|----------|----------|-----------|-------------|---|---|
| **Question 6: Have you changed the place where you live since COVID-19 and the lockdown started?** | | | | |
| Total answers (n = 582) | 525 (90.2) | 57 (9.8) | | | |
| Gender | | | | |
| Male (n = 279) | 254 (91.0) | 25 (9.0) | 0.42 | .516 | .03 |
| Female (n = 303) | 271 (89.4) | 32 (10.6) | | | |
| Age group | | | | |
| Up to 21 years old (n = 84) | 79 (94.0) | 5 (6.0) | 4.2 | .122 | .08 |
| Between 22 and 44 years old (n = 344) | 313 (91.0) | 31 (9.0) | | | |
| 45 years old or more (n = 154) | 133 (86.4) | 21 (13.6) | | | |
| Housing type | | | | |
| Family/own home (n = 464) | 431 (92.2) | 33 (7.1) | 18.9 | <.001 | .18 |
| Disability-related services (n = 106) | 85 (80.2) | 21 (19.8) | | | |
| Another place (n = 12) | 9 (75.0) | 3 (25.0) | | | |
| Occupation | | | | |
| Study (n = 135) | 124 (91.9) | 11 (8.1) | 1.5 | .678 | .05 |
| Work (n = 195) | 178 (91.3) | 31 (9.0) | | | |
| Study and work (n = 42) | 37 (88.1) | 5 (11.9) | | | |
| Neither work nor study (n = 210) | 186 (88.6) | 24 (11.4) | | | |
| **Question 8: Can you study remotely without difficulties? (only for students)** | | | | |
| Total answers (n = 171) | 82 (48.0) | 89 (52.0) | | | |
| Gender | | | | |
| Male (n = 81) | 40 (49.4) | 41 (50.6) | 0.13 | .723 | .03 |
| Female (n = 90) | 42 (46.7) | 48 (53.3) | | | |
| Age group | | | | |
| Up to 21 years old (n = 68) | 39 (57.4) | 29 (42.6) | 4.0 | .135 | .15 |
| Between 22 and 44 years old (n = 93) | 39 (41.9) | 54 (58.1) | | | |
| 45 years old or more (n = 10) | 4 (40.0) | 6 (60.0) | | | |
| Housing type | | | | |
| Family/own home (n = 150) | 69 (46.0) | 81 (54.0) | 1.0 | .316 | .08 |
| Disability-related services (n = 17) | 10 (58.8) | 7 (41.2) | | | |
| Another place (n = 4)* | 3 (75.0) | 1 (25.0) | | | |
| **Question 10: Have you been able to continue working without difficulties? (only for workers)** | | | | |
| Total answers (n = 231) | 168 (72.7) | 63 (27.3) | | | |
| Gender | | | | |
| Male (n = 115) | 78 (67.8) | 37 (32.2) | 2.77 | .096 | .10 |
| Female (n = 116) | 90 (77.6) | 26 (22.4) | | | |
| Age group | | | | |
| Up to 21 years old (n = 5) | 5 (100) | 0 (0) | 3.6 | .059 | .11 |
| Between 22 and 44 years old (n = 154) | 117 (76.0) | 37 (24.0) | | | |
| 45 years old or more (n = 72) | 46 (63.9) | 26 (36.1) | | | |
| Housing type | | | | |
| Family/own home (n = 150) | 133 (72.3) | 51 (27.7) | 0.04 | .841 | .01 |
| Disability-related services (n = 17) | 31 (73.8) | 11 (26.2) | | | |
| Another place (n = 4)* | 4 (80.0) | 1 (20.0) | | | |

*Another place’ was not included in the independence analyses for questions 8 and 10 because it contributed to have two cells (33.3%) with \( n < 5. \)

Percentages in bold indicate the level of the variable for which the standardised residual exceeded \( \pm 1.96 \) z scores, indicating that the existing relationship occurred for that response category.

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Table 6  Participants’ responses by sociodemographic characteristics to questions exploring ‘access to support to face the crisis’

| Variable                                                                 | N  | No (%)  | N  | Yes (%)  | \(\chi^2\) | p   | V    |
|--------------------------------------------------------------------------|----|---------|----|----------|------------|-----|------|
| **Question 12: Are you receiving help or support to face the lockdown?**  |    |         |    |          |            |     |      |
| Total answers (n = 582)                                                   | 104 | (17.9)  | 478 | (82.1)   |            |     |      |
| Gender                                                                   |    |         |    |          |            |     |      |
| Male (n = 279)                                                            | 56  | (20.1)  | 223 | (79.9)   | 1.8        | .183 | .06  |
| Female (n = 303)                                                          | 48  | (15.8)  | 255 | (84.2)   |            |     |      |
| Age group                                                                |    |         |    |          |            |     |      |
| Up to 21 years old (n = 84)                                               | 11  | (13.1)  | 73  | (86.9)   | 2.4        | .297 | .06  |
| Between 22 and 44 years old (n = 344)                                     | 68  | (19.8)  | 276 | (80.2)   |            |     |      |
| 45 years old or more (n = 154)                                            | 25  | (16.2)  | 129 | (83.8)   |            |     |      |
| Housing type                                                              |    |         |    |          |            |     |      |
| Family/own home (n = 464)                                                | 89  | (19.2)  | 375 | (80.8)   | 2.8        | .244 | .07  |
| Disability-related services (n = 106)                                     | 13  | (12.3)  | 93  | (87.7)   |            |     |      |
| Another place (n = 12)                                                    | 2   | (16.7)  | 10  | (83.3)   |            |     |      |
| Occupation                                                                |    |         |    |          |            |     |      |
| Study (n = 135)                                                           | 104 | (20.0)  | 478 | (80.0)   | 2.9        | .414 | .07  |
| Work (n = 195)                                                            | 36  | (18.5)  | 159 | (81.5)   |            |     |      |
| Study and work (n = 42)                                                   | 10  | (23.8)  | 32  | (76.2)   |            |     |      |
| Neither work nor study (n = 210)*                                         | 31  | (14.8)  | 179 | (85.2)   |            |     |      |
| **Question 13: Do you miss someone or are you missing something to help you face this situation better?** |    |         |    |          |            |     |      |
| Total answers (n = 582)                                                   | 52  | (8.9)   | 530 | (91.1)   |            |     |      |
| Gender                                                                   |    |         |    |          |            |     |      |
| Male (n = 279)                                                            | 30  | (10.8)  | 249 | (89.2)   | 2.2        | .140 | .06  |
| Female (n = 303)                                                          | 22  | (7.3)   | 281 | (92.7)   |            |     |      |
| Age group                                                                |    |         |    |          |            |     |      |
| Up to 21 years old (n = 84)                                               | 7   | (8.3)   | 77  | (91.7)   | 0.04       | .978 | .1   |
| Between 22 and 44 years old (n = 344)                                     | 31  | (9.0)   | 313 | (91.0)   |            |     |      |
| 45 years old or more (n = 154)                                            | 14  | (9.1)   | 140 | (90.9)   |            |     |      |
| Housing type                                                              |    |         |    |          |            |     |      |
| Family/own home (n = 464)                                                | 44  | (9.5)   | 420 | (90.5)   | 1.6        | .449 | .05  |
| Disability-related services (n = 106)                                     | 8   | (7.5)   | 98  | (92.5)   |            |     |      |
| Another place (n = 12)                                                    | 0   | (0)     | 12  | (100)    |            |     |      |
| Occupation                                                                |    |         |    |          |            |     |      |
| Study (n = 135)                                                           | 13  | (9.6)   | 122 | (90.4)   | 1.1        | .782 | .04  |
| Work (n = 195)                                                            | 178 | (8.7)   | 178 | (91.3)   |            |     |      |
| Study and work (n = 42)                                                   | 2   | (4.8)   | 40  | (95.2)   |            |     |      |
| Neither work nor study (n = 210)*                                         | 20  | (9.5)   | 190 | (90.5)   |            |     |      |
| **Question 14: Are you receiving help or support to study remotely? (only for students)** |    |         |    |          |            |     |      |
| Total answers (n = 171)                                                   | 73  | (42.7)  | 98  | (57.3)   |            |     |      |
| Gender                                                                   |    |         |    |          |            |     |      |
| Male (n = 81)                                                             | 31  | (38.3)  | 50  | (61.7)   | 1.2        | .268 | .08  |
| Female (n = 90)                                                           | 42  | (46.7)  | 48  | (53.3)   |            |     |      |
| Age group                                                                |    |         |    |          |            |     |      |
| Up to 21 years old (n = 68)                                               | 14  | (20.6)  | 54  | (79.4)   | 28.8       | <.001 | .41  |
| Between 22 and 44 years old (n = 93)                                       | 57  | (61.3)  | 36  | (38.7)   |            |     |      |
| 45 years old or more (n = 10)                                             | 2   | (20.0)  | 8   | (80.0)   |            |     |      |
| Housing type                                                              |    |         |    |          |            |     |      |
| Family/own home (n = 150)                                                | 64  | (42.7)  | 86  | (57.3)   | 0.12       | .729 | .03  |
| Disability-related services (n = 17)                                      | 8   | (47.1)  | 9   | (52.9)   |            |     |      |
| Another place (n = 4)*                                                   | 1   | (25.0)  | 3   | (75.0)   |            |     |      |
| **Question 16: Have you missed support to help you maintain your well-being?** |    |         |    |          |            |     |      |
| Total answers (n = 582)                                                   | 454 | (78.0)  | 128 | (22.0)   |            |     |      |
| Gender                                                                   |    |         |    |          |            |     |      |
United Nations (2020) and Spanish organisations (Spanish Committee on Representatives of Persons with Disabilities 2020): (1) access to information on COVID-19 and the subsequent lockdown, (2) emotional experiences, (3) the effects of the situation on living conditions and (4) access to support during this period.

Spaniards with IDD perceived that their access to information and support was good overall. Regarding access to information, most participants reflected having received information about COVID-19 (89.5%) and having understood it (81.0% of whom received it), in addition to having understood the reason for the lockdown (81.7%). Although concluding how effective this information is not possible because this study only analysed participants’ perceptions, this finding may reflect the efforts made by service providers in Spain to share accessible information about the coronavirus and the measures taken to fight it. For example, during the lockdown, Plena inclusión held 20 informative seminars on the situation and developed around 80 documents in easy-to-read formats (e.g. Plena inclusión 2020c). Participants have also stated that they have received supports to deal with the situation. In this regard, the rapid response of organisations since the beginning of the pandemic, with the development of support guidelines adapted to different realities (e.g. Plena inclusión 2020a, 2020b), helps to understand this finding.

Participants reported difficulties with their emotional experiences and maintaining their work or study. Similar to the findings of Drum et al. (2020), nearly 60% of participants reported feeling fearful or more anxious since the beginning of the lockdown. These findings suggest the need for increased support to address the emotional difficulties experienced by people with IDD in this situation. The establishment of online support networks could help mitigate these effects. The experience in the Netherlands has shown that people with IDD increased their access to this kind of support during the first weeks of the pandemic, when they were more likely to feel fear or anxiety of the unknown (Zaagsma et al. 2020). In line with the findings of Embregts et al. (2020), Spaniards with IDD also reported interruptions in their occupations (48.0% of students and 72.7% of workers).

Apart from the general findings, the analysis of responses in relation to sociodemographic characteristics and completion method enabled the identification of characteristics (e.g. age, living situation or occupation) related to participants’ perceptions about the effects of COVID-19 and the subsequent lockdown. This will help to focus the

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Table 6. (Continued)

| Variable                                      | N No (%) | N Yes (%) | χ²   | p     | V    |
|-----------------------------------------------|----------|-----------|------|-------|------|
| Male (n = 279)                                | 213 (76.3) | 66 (23.7) | 0.86 | .353  | .04  |
| Female (n = 303)                              | 241 (79.5) | 62 (20.5) |      |       |      |
| Age group                                     |          |           |      |       |      |
| Up to 21 years old (n = 84)                   | 53 (63.1) | 31 (36.9) | 13.6 | .001  | .15  |
| Between 22 and 44 years old (n = 344)         | 273 (79.4) | 71 (20.6) |      |       |      |
| 45 years old or more (n = 154)                | 128 (83.1) | 26 (16.9) |      |       |      |
| Housing type                                  |          |           |      |       |      |
| Family/own home (n = 464)                    | 362 (78.0) | 102 (22.0) | 0.99 | .608  | .04  |
| Disability-related services (n = 106)         | 84 (79.2) | 22 (20.8) |      |       |      |
| Another place (n = 12)                       | 8 (66.7)  | 4 (33.3)  |      |       |      |
| Occupation                                    |          |           |      |       |      |
| Study (n = 135)                               | 94 (69.6) | 41 (30.4) | 9.5  | .024  | .13  |
| Work (n = 195)                                | 158 (81.0) | 37 (19.0) |      |       |      |
| Study and work (n = 42)                      | 30 (71.4)  | 12 (28.6) |      |       |      |
| Neither work nor study (n = 210)              | 172 (81.9) | 38 (18.1) |      |       |      |

*Another place’ was not included in the independence analysis for question 14 because it contributed to have two cells (33.3%) with n < 5.

Percentages in bold indicate the level of the variable for which the standardised residual exceeded ±1.96 z scores, indicating that the existing relationship occurred for that response category.
discussions and proposals as new literature on the topic emerges.

Regarding the statistical relationship between participants’ sociodemographic characteristics and their answers, young people with IDD (38.6%) and students (27.2%) perceived greater difficulty in understanding COVID-19 information, and 25.0% of young people found it difficult to understand the reason for the lockdown. This finding suggests that, despite the efforts, the information was not disseminated to everyone equally. The literature reveals strategies that should be considered to maximise access to information for people with IDD. First, given that people with IDD represent a heterogeneous group, information resources should be developed in a range of formats and versions appropriate for different levels of ability (Lennox et al. 2005; Mulhall et al. 2019), support needs (Thompson et al. 2018) and learning styles (Buchanan 2017). Second, people with IDD should be involved in developing these resources (EASPD 2020). Finally, it is essential to use an appropriate information dissemination strategy that considers the characteristics of the target group (e.g. age and motivational and learning styles) and is updated, proactive and preventive (Meltzer 2020). Maryanti et al. (2020) provide an example of how these considerations may help in the dissemination of information while empowering people with IDD to combat the virus.

With respect to emotional experiences, being female was weakly related to being more fearful and

| Question                                                                 | Direct | Indirect |
|--------------------------------------------------------------------------|--------|----------|
| Did you receive information on COVID-19? *                              | 331 (88.7) | 42 (11.3) |
| Was this information easy for you to understand? †                      | 291 (87.9) | 40 (12.1) |
| Did you understand why the government has decided that we cannot go out?‡ | 349 (93.6) | 24 (6.4)  |
| Have you been frightened these days because of COVID-19? †               | 220 (59.0) | 153 (51.0) |
| Have you been more nervous than usual these days because of COVID-19?‡   | 212 (56.8) | 161 (43.2) |
| Have you changed the place where you live since COVID-19 and the lockdown started?‡ | 36 (9.7) | 337 (90.3) |
| Can you study remotely without difficulties? (only for students)†        | 70 (62.5) | 42 (37.5)  |
| Have you been able to continue working without difficulties? (only for workers)‡ | 46 (26.9) | 125 (73.1) |
| Are you receiving help or support to face the lockdown‡                  | 287 (76.9) | 86 (23.1)  |
| Do you miss someone or are you missing something to help you face this situation better?‡ | 337 (90.3) | 36 (9.7)  |
| Are you receiving help or support to study remotely? (only for students)§ | 48 (42.9) | 64 (57.1)  |
| Have you missed support to help you maintain your well-being?§           | 61 (16.4) | 312 (83.6) |

Questions addressing research topics:
* Access to information.
† Emotional experiences during the lockdown.
‡ Effects on living conditions.
§ Access to support to face the crisis.

Table 7: Relationships between completion method and participants’ responses

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anxious. In the absence of studies analysing the psychological consequences of the pandemic for people with IDD, this finding is consistent with studies on the general psychological response to the pandemic, which have shown that women are more likely to experience a poorer adjustment compared with men (e.g. Moghanibashi-Mansourieh 2020; Zou et al. 2020). More research is necessary to understand the potential gender-related variables affecting the psychological adjustment of individuals with IDD in challenging circumstances. Living context was associated with being more anxious during the pandemic, especially for 65.1% of the participants who lived in organisational housing services. The challenges related to living in residential facilities in Spain help shed light on this finding. Indeed, organisations providing these services have reported to have been overwhelmed because of the lack of resources to prevent contagion between carers and people with IDD and the lack of time to prepare and explain the measures taken. Consequently, many people with IDD have experienced sudden changes in their environments, including changes in the professionals providing support to them, the people with whom they live (because of isolations and quarantine) and their routines (Corretjè 2020; Plena inclusión 2020b). This helps to explain why almost 10% of participants changed their living situation at the onset of the lockdown, in most cases moving from organisational facilities to their family homes.

The lockdown has interrupted the occupations of both students and workers. The results from students are striking – approximately half have been unable to follow online education, and although nearly 60% have received educational support, professional support has been lacking and the responsibility for this has fallen primarily on families. This highlights the burden for families in terms of supporting their relatives with IDD, the poor preparation of educational systems for the online education of individuals with IDD and the need for family–school collaboration to support students (Esentürk 2020). Since the start of the lockdown, experts have highlighted that the Spanish educational system’s poor preparation for online education may increase the education gap experienced by vulnerable students (Cáceres-Muñoz et al. 2020; Espinosa 2020). Nevertheless, 3 months after schools have reopened, there remains a lack of data on the experiences of students with IDD. Thus, research on the education of students with IDD is needed for two reasons: (1) to address the challenges faced by students with IDD and their needs following lockdown and (2) to analyse the indicators (e.g. percentage of students with IDD attending general education at the beginning vs. the end of the academic year) to determine whether the education gap has increased since the lockdown. This would enable the identification of priority areas to support students with IDD and mitigate the potential negative effects of the lockdown.

The burden suffered by Spanish organisations during the first wave of COVID-19 helps explain why 36.9% of those younger than 21 years and 30.4% of students reported a lack of support to maintain their well-being. Organisations have had to prioritise support for people with IDD living in residential facilities (Plena inclusión 2020b) over the support for younger people and students, most of whom live with their families (Navas et al. 2017). This finding should raise awareness for organisations of the need to reinforce their support for young people with IDD regardless of their living context. This is critical given that the mission of most Spanish disability support organisations is to enhance the well-being of their clients at all stages of their lives (Verdugo 2018; González 2019).

There was a clear trend in the relationship between participants’ responses and completion method (i.e. direct vs. indirect), with a strong and significant relationship between the need for a third party to complete the survey via an interview and responses reflecting poorer outcomes. It may be hypothesised that those who answered the survey via an interview did so because they had greater support needs, preventing them from completing an online survey. These participants’ responses may reflect their need for more intensive and persistent support when facing the demands posed by COVID-19 and the lockdown than is required by their counterparts. However, this can only be hypothesised because the only certainty about the completion method was the way in which answers were provided, and other interpretations may exist (e.g. lack of access to technology). For this reason, the authors of the present study did not further stratify the analyses under the assumption that the means of answering the survey reflected the participants’ support needs.
This work has some limitations that should be considered. The primary limitation was the lack of collection of data on participants’ personal functioning. Specifically, without the inclusion of a ‘support needs’ variable, it is impossible to control for the confounding effects that it may have introduced in the results. The research team decided not to collect this information because of the potential difficulty of some individuals to provide it and to avoid stigmatisation. Another limitation refers to the sampling method. Despite the large number of respondents, the sample was not stratified, which may affect the generalisability of the results. Third, because the survey was voluntary and online, those with difficulties accessing technology or without a support person to help them complete the survey are likely to have been under-represented. Fourth, each topic was analysed using a relatively small number of questions, and although the literature highlights the need for people with IDD to be given a voice, studying their perceptions does not mean analysing the phenomenon in depth. For these reasons, the findings reported in this study should be regarded as preliminary and a foundation for future research.

The work also has strengths. First, although the findings reflect the experiences of Spaniards with IDD, they also have international relevance. Findings on the relationships between sociodemographic characteristics (i.e. living context, age or occupation) and participants’ perceptions may be informative for other researchers. They may also help authorities better respond to the needs of social services and people with IDD during successive waves. It is also worth stressing that most participants were able to personally complete the online survey. This should encourage future researchers to use this technology more often in order to include people with IDD in their studies. Finally, the design of the survey involved all relevant stakeholders, including people with IDD.

In addition to the lines of research already mentioned, a future line of research should help to overcome the duality found in the literature. So far, studies have focused on the effects of COVID-19 and lockdown from the perspectives of people with IDD (e.g. Drum et al. 2020; Embrégts et al. 2020) or their carers (e.g. Esentürk 2020; Neece et al. 2020). However, studies exploring the effects of the pandemic and subsequent lockdown on families as a whole (e.g. how family circumstances such as economic status may influence the perceptions of both people with IDD and their carers) are lacking. This would provide a more comprehensive understanding of the situation to act accordingly.

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Conflict of Interest

Nothing to declare.

Data Availability Statement

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

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