



COVID-19

A report on the situation of
intersex people in Europe
and Central Asia

Dan Christian Ghattas

Questionnaire developed by Irene Kuzemko

COVID-19. A report on the situation of intersex people in Europe and Central Asia.

Dan Christian Ghattas

with Irene Kuzemko

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This report is part of a global study on the situation of intersex people and their families in times of Covid-19, initiated by OII Europe and conducted by the International Intersex Community in different regions of the world. The global report will be published in 2021.

Authored by: Dan Christian Ghattas

Questionnaire developed by: Irene Kuzemko

Proof Reading: Cianán Russel

Proof reading of the questionnaire: Magda Rakita, Dan Christian Ghattas

Quantitative analyses of findings: Irene Kuzemko, Dan Christian Ghattas

Layout & Graphs: Ins A Kromminga

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Introduction

The still ongoing Covid-19 pandemic has had a massive impact on people all around the world. With this survey we assessed the impact of the pandemic specifically on the lives of intersex people and their families in Europe.

Many surveys on the impact of Covid-19 were developed and launched after the beginning of the crisis, but even when they addressed areas that are of particular concern for intersex people and their families, the still prevailing lack of awareness about intersex people and intersex lives makes it challenging for these surveys to collect meaningful data or to collect data at all. Many intersex people have reported to OII Europe that the available Covid-19 surveys did not address the specific challenges created or aggravated for them by Covid-19.

As OII Europe, with the support of the European Intersex Community, we therefore set out to create a questionnaire that would help to gather more detailed information about important areas of the lives of intersex people and their families in the times of Covid-19.

We decided used quantitative data collection together with extensive opportunity for participants to write about their experience. From a statistical point of view, the quantitative findings are not applicable to the general intersex population, as the sample size is too small and the necessary statistical randomness is not given. But they send a signal and indicate areas of concern.

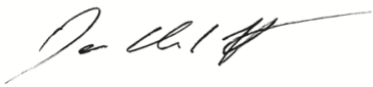
The quantitative and qualitative data together strongly point towards intersex people being a highly vulnerable part of the population in the context of Covid-19. One of the most important findings in this respect is the highly increased risk for intersex people to not be able to access health care due to their history of medical trauma, even when infected with Covid-19.

The high percentage of increased mental health issues amongst the respondents represents another worrying (though not surprising) finding, as mental health issues acquired by intersex people through the violations of their physical and psychological integrity and through the stress of living invisible, in isolation and with stigma and taboo make intersex individuals more vulnerable. In addition, the pre-existing lack of educated psychological counselling makes it harder for intersex people to receive help; this situation has been aggravated during the Covid-19 crisis.

These results are in line with surveys and studies about the increased vulnerability of minority groups in times of a pandemic and Covid-19.¹ Minority stress, caused by discrimination experienced in every day life as well as the economic and social inequalities caused by structural discrimination act as a negatively aggravating factor on the capacity of individuals to stay physically and mentally health in such times of crisis. The findings of this exploratory study mirror these well-known facts to a worrying extent and therefore make a strong call for the need for further, educated and intersex-focussed research.

We want to full heartedly thank the members of the European Intersex Community who responded to this survey, the intersex individuals who supported OII Europe in the development of the questionnaire, and last but not least our incredible translators.

Dan Christian Ghattas



Executive Director OII Europe

¹ See:

Charlotte Gayer-Anderson, Rachel Latham, Catherine El Zerbi et. al. (2020): Impacts of social isolation among disadvantaged and vulnerable groups during public health crises. Ed. by ESRC Centre for Society & Mental Health, King's College London <https://esrc.ukri.org/files/news-events-and-publications/evidence-briefings/impacts-of-social-isolation-among-disadvantaged-and-vulnerable-groups-during-public-health-crises/>

Annesa Flentje, Juno Obedin-Maliver, Micah E. Lubensky, Zubin Dastur, Torsten Neilands, Mitchell R. Lunn (2020): Depression and Anxiety Changes Among Sexual and Gender Minority People Coinciding with Onset of COVID-19 Pandemic <https://storage.googleapis.com/pride-assets-prod/site-pages/reference/journal-of-general-internal-medicine-june-18-2020.pdf>

Ibraheem M. Karaye, Jennifer A. Horney (2020): The Impact of Social Vulnerability on COVID-19 in the U.S.: An Analysis of Spatially Varying Relationships. Am J Prev Med 2020;59(3):317–325 <https://www.ajpmonline.org/action/showPdf?pii=S0749-3797%2820%2930259-2>

IE SOGI (2020): Report to the UN General Assembly. The Impact of the Covid-19 Pandemic on the Human Rights of LGBT Persons <https://www.ohchr.org/Documents/Issues/SexualOrientation/ImpactCOVID19LGBTpersons.pdf>

Human Rights Campaign Foundation (2020): The Economic Impact of Covid-19 on the LGBTQ Community. <https://assets2.hrc.org/files/assets/resources/COVID19-EconomicImpact-IssueBrief-042220.pdf>

Methodology

The survey was launched on 01 July 2020 through multiple communication channels of the European Intersex Community and was open for approximately one month, until 03 August 2020.

Questionnaire

The development of the questionnaire was based on an exploratory qualitative pilot, based on one-on-one and focus group interviews with intersex individuals and their families, starting from the beginning of the Covid-19 crisis and continuing throughout the development of the questionnaire. The exploratory study led to the development of a comprehensive set of questions and pre-determined responses to many of these. The questionnaire was then sent for review to 6 intersex people from all Council of Europe sub-regions, to allow for a maximum of inclusion of the diversity of issues relevant to different European regions.

In addition to the pre-determined answers, 40 out of 46 questions had an open text option, which was used extensively by the participants to give more details or, in some few cases, to add additional responses. Many of the question were set up as multiple mark to allow respondents to capture different parts of their experience.

The questionnaire consists of a set of 46 questions, which cover the impact of Covid-19 in the following areas of life:

- Physical and Mental Health and Wellbeing (including e.g., questions about general access to health, access to health related to a possible Covid-19 infection, access to medication)
- Access to Support (including e.g., questions about peer support, financial support, other kind of support)
- Financial Situation and Housing (including e.g., general questions about income shifts and the reasons for it, shifts of expenses, governmental financial support)
- Traveling (including e.g., the possible impact of restrictions on intersex activism)
- Education (including e.g., the impact of online learning)
- Personal Safety (including e.g., at home during lockdowns, when seeking access to health services)
- Intersex Activism

In addition, the questionnaire asked about

- Whether the respondent was an intersex person or a family member of an intersex person
- Country of residence
- Areas of life that the respondents felt were most impacted by Covid-19
- Aspects of the respondent's life which add to their vulnerability

- Challenges in regards to participating in the “new normal” (i.e., online based communication and internet access)
- Perspectives on future developments, access to vaccine and specific sub-regional issues

A *special focus* was put on the area of health and the area of work, as these had been identified already before the development of the questionnaire as being particularly challenging for intersex individuals in times of Covid-19.

In order to *protect the privacy* of intersex individuals and their families, we abstained from collecting any demographic data that was not directly needed for the purpose of the survey. In addition, the three last questions of the survey asked for consent to quote from the open-ended responses in reports; only the responses of those who consented are quoted in this report.

Self-selection of respondents and dissemination of the questionnaire

The questionnaire was brought to the attention of intersex people within the European Intersex Community. It was disseminated through OII Europe’s communication channels (email, social media) to OII Europe member organisations and participants of the OII Europe Community Events & Conferences 2017, 2018 and 2019, as well as other individuals active on OII Europe’s closed FB groups. These individuals furthered the dissemination of the questionnaire within their organisations and networks (social media as well as in-person) of intersex individuals and their families (snowball sampling).

The decision to not publish the call openly, e.g., on social media, was taken to prevent the questionnaire to be misused by interest groups like the anti-gender movement - a risk that has become increasingly prominent in the past few years for surveys addressing needs of the LGBTI spectrum in general.

Intersex people as well as parents, partners, care-takers and close family members of intersex individuals were encouraged to fill out the survey based on the rationale that, for example, intersex children are directly affected if their parents and care-takers suffer from, e.g., income loss as a result of the pandemic. For instance, medications may become unaffordable due to decreases in family income. The same can be true for intersex adults, especially if a partner of an intersex person is the main earner (due to impairments the intersex person may have acquired due unwished medical treatment, for example), or if a partner provides health insurance for both.

Language

The questionnaire was made available in 7 languages: English, German, Greek, French, Polish, Russian, and Turkish.

Technical tools used

Survey Monkey Pro was used as a tool to set up the questionnaire and to collect results. Final calculations of percentages were done in Excel to circumvent some of the limitations set by Survey Monkey.

Definition of “intersex” used for this survey

The survey focusses on the situation of intersex people/ people with variations of sex characteristics and their families. The terms *intersex people/people with variations of sex characteristics* were defined as follows and the definition was communicated during the dissemination of the survey:

The term “intersex” is an umbrella term for the spectrum of variations of sex characteristics that naturally occur within the human species. The term intersex acknowledges the fact that physically, sex is a spectrum and that people with variations of sex characteristics other than male or female exist. Intersex individuals are born with sex characteristics (sexual anatomy, reproductive organs, hormonal structure and/or levels and/or chromosomal patterns) that do not fit the typical definition of male or female.

The fact that someone has an intersex body can become apparent to them at different times in their life: at birth, during childhood, in puberty or even in adulthood. Depending on the specific life circumstances and the degree of taboo in their environment, a person might learn that they have an intersex body at a very early age or later in life. Some intersex people never find out at all.

Denominator used in the report

The denominator used is always n= total number of respondents unless specifically otherwise noted.

Use of bar-charts in the report

The bar-charts aim to allow for an easy overview of trends. The numbers cannot be generalized for the total intersex population of Europe and Central Asia.

Limits of the survey

General limits of statistical validity

From a statistical point of view, the sample size of the survey was too small and the necessary statistical randomness was not given, to begin with. Additionally, a snowball sampling method has inherent limitations in generalisability. As a result, the quantitative findings are not applicable to the general intersex population. However, the numbers and percentages can be treated as indicators for trends. They are a signal and indicate areas of concern where more research is needed.

Unit non-response

As shown below the response rate of the sub-regions, for example, differs substantially. The exploratory character of this survey does not allow any meaningful use of statistical methods like applying sampling weight and an unknown response probability.

While the smallness of the sample size and the lack of initial statistical randomness does not allow for a statistical weighting and a valid comparison between the sub-regions, some findings of gaps may still be important food for thought and further research. In the following report they are highlighted for these reasons, but with the clear reservation that the basic limitations of the survey do not allow any balanced comparison.

Item non-response

Missing answers or item non-response are a well-known issue with quantitative data collection and this survey is no exception: survey respondents skipped questions, including questions that provided a box “not-applicable”. Different statistical processes exist, like imputation or complete-case analysis, to handle missing values. However, the exploratory character of this survey does not allow to use these processes in a meaningful way. Therefore, skipping a question is dealt with as if the respondent had ticked the box “non-applicable”.

Accessibility of the survey

Due to time constraints this survey was launched as an online survey only. No other means (e.g., a paper version) were provided for filling it out. Intersex people and their families without access to the internet or without a support network that could help them to fill in the questionnaire were not reached by this survey.

In regards to diverse accessibility needs, the survey, unfortunately, depended on the technical means provided by the available online tools: Survey Monkey allows access for screen readers; hence the survey was available to persons who use this device. Unfortunately, no human resources were available to provide versions in easy language. The limited number of translations certainly also prevented individuals to take the survey.

The Baseline – Intersex realities before the Covid-19 pandemic

Even before the pandemic, intersex people were among the most vulnerable groups of the general population. Comprehensive statistical data on the life situation of intersex people across the Council of Europe region and Central Asia is still to be collected. For EU Members States, however, the findings of the EU Fundamental Rights Agency 2019 LGBTI Survey² and the findings available through the FRA Data Explorer³ have shown that intersex people stand out - even when looking at the LGBTI spectrum - as a sub-group of the population which experiences a high level of discrimination across Europe.

According to the FRA findings, 62% of intersex respondents, almost two thirds, felt discriminated against in at least one area of life in the 12 months before the survey. 27% of intersex respondents to the survey reported experiencing violent in-person threats six times or more and another 38% reported at least one such attack in the year before the FRA survey.

14% of intersex youth age 15-17 reported physical or sexual attacks and of those, more than 50% of those respondents were affected severely, causing psychological problems like depression or continuous anxiety.

In addition, among all LGBTI respondents, intersex people are the group with the highest rates of difficulties in the area of housing and economic stability: 29% of intersex respondents experienced housing difficulties, the highest rate among all LGBTI respondents, with 41% stating relationship or family problems as reason for the housing difficulties. 37%, however, said they experienced housing difficulties due to financial problems and insufficient income. Not surprisingly 51% of intersex respondents confirmed that their household's total income makes making ends meet difficult.

As we know, all those factors can already cause severe challenges for a person's mental health. To this we need to add the burden of having been subjected to surgeries and other medical treatment without prior, personal, free and fully informed consent, which between 62% and 49% of the respondents who were subjected to surgeries and other medical treatments, respectively, did not provide. Turning to the aspect of support however, the findings show that there is a severe gap: When trying to access help for their mental or physical health, 35% of intersex people faced discrimination from health services.

With this baseline being worrying already, the situation has aggravated through Covid-19 as the following report will show.

² European Union Agency for Fundamental Rights (FRA): EU-LGBTI II (2019) Survey Report "A long way to go for LGBTI equality" https://fra.europa.eu/sites/default/files/fra_uploads/fra-2020-lgbti-equality-1_en.pdf

³ European Union Agency for Fundamental Rights (FRA): LGBTI Survey Data Explorer <https://fra.europa.eu/en/data-and-maps/2020-lgbti-survey-data-explorer>; the following findings for different areas have been collected from the LGBTI Survey Data Explorer and can be found on OII Europe's Infographics: <https://oieurope.org/library-en/infographics/>

Findings – The situation of intersex people in Europe and Central Asia in Covid-19 times

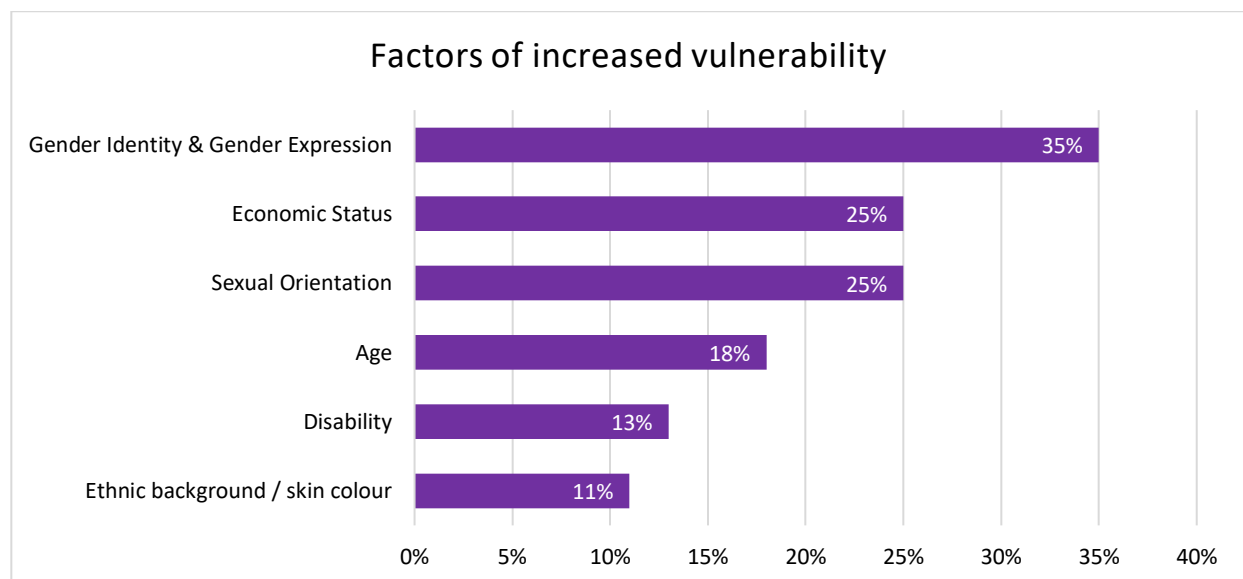
Regional representation and respondent matrix

The survey was filled out by 63 intersex people, including 6 minors,⁴ and 3 family members of intersex people, coming from 16 countries from Europe and Central Asia:

- *Eastern Europe, the Balkans and Central Asia (31 intersex respondents):* Bulgaria, Belarus, Kazakhstan, Poland, Russia, Serbia, Ukraine
- *South-Eastern Europe (15 intersex respondents, 2 family members):* Greece, Turkey
- *Western Europe and Nordic countries (17 intersex respondents, 1 family member):* Austria, Belgium, Finland France, Germany, Netherlands, Switzerland

Intersectional Realities and Aggravated Challenges

Like everyone, intersex people live their lives in the intersection of different aspects of their identity and lived realities. As the past months have shown, fundamental rights are easily breached in times of crisis, and harassment, discrimination and other forms of violence increase in times of general struggle and angst. While being already very vulnerable as a result of being born with variations of sex characteristics, other factors can amplify the challenges.

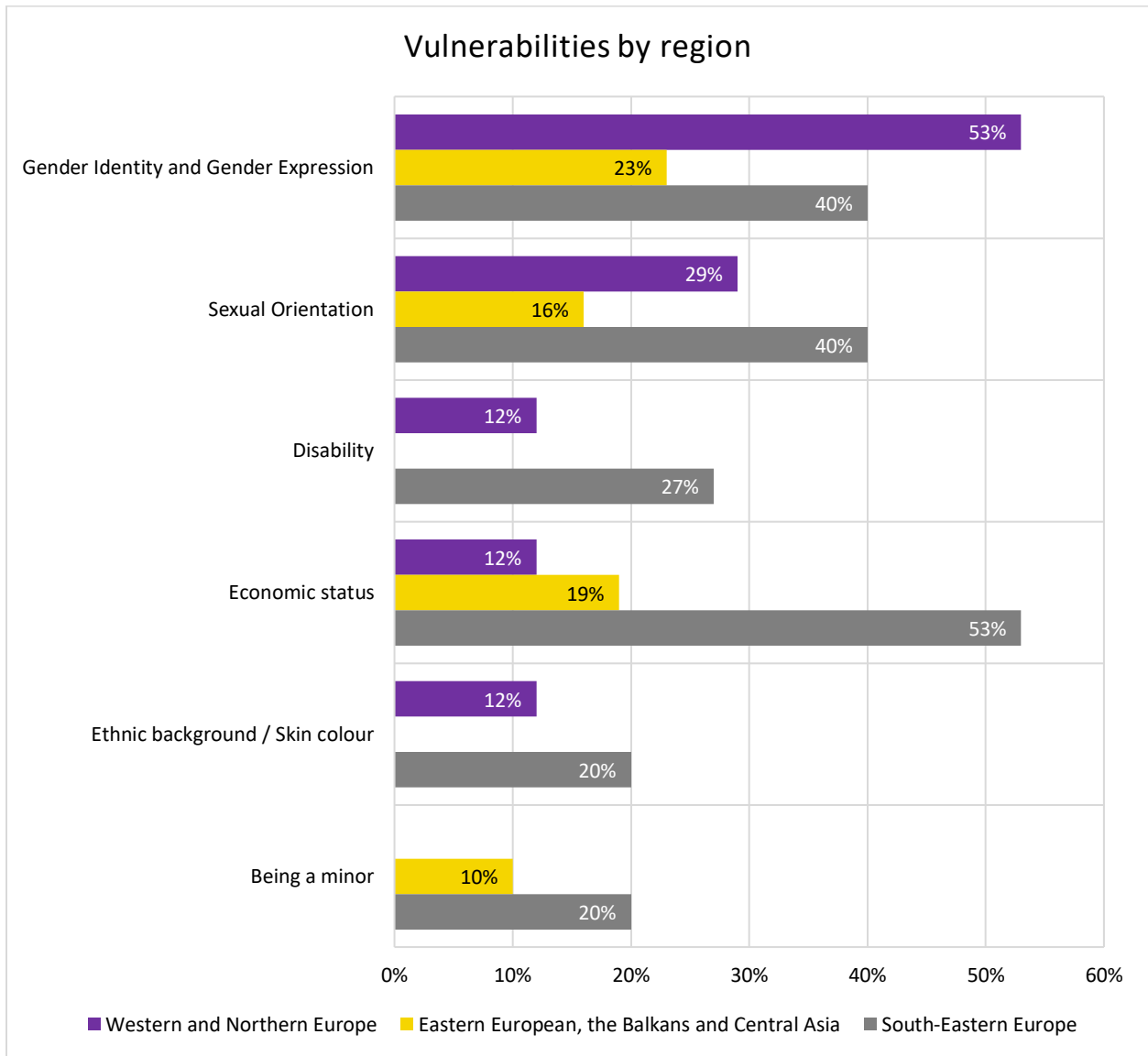


Out of all intersex people respondents, more than a third (35%) stated that their gender identity and gender expression amplified their vulnerability and a quarter felt intersex respondents felt that their economic status (25%) and their sexual orientation (25%) increased their vulnerability.

⁴ Two of the minors were helped by an adult family member to fill out the questionnaire.

Age (18%), disability (13%) and ethnic background/ skin colour (11%) were stated as additional factors.

Some regions showed a shift towards a bigger prominence of certain aspects regarding vulnerabilities that intersect with the vulnerability of respondents of being intersex or a family member of an intersex person.



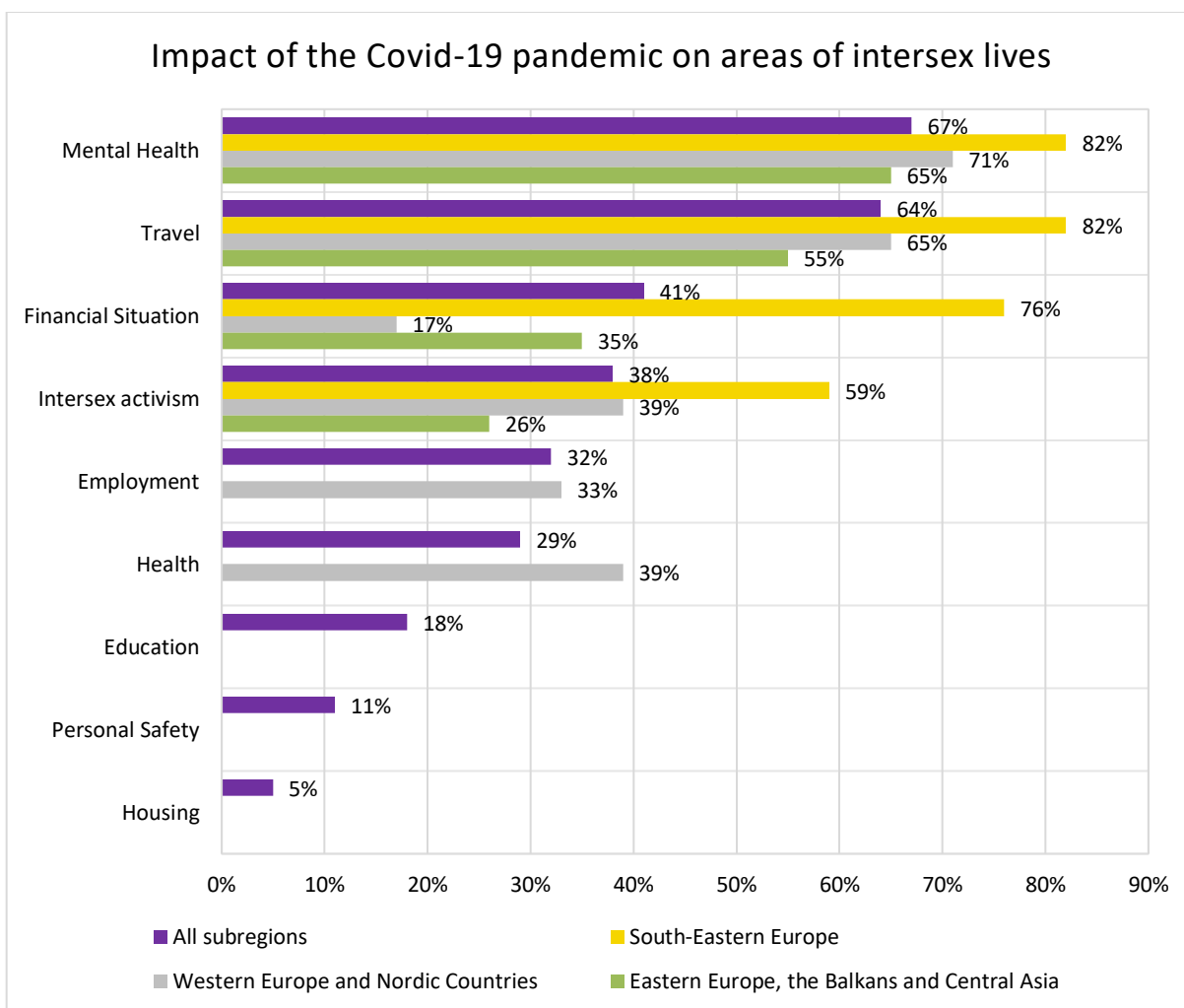
Gender identity and gender expression, for example, were identified as an intersecting area by 53% of intersex respondents from *Western and Northern Europe*, followed by sexual orientation (29%) and disability, economic status and ethnic background/skin colour (each 12%).

Many intersex respondents from *Eastern European, the Balkans and Central Asia* found their gender identity and gender expression to aggravate their vulnerability as an intersex person

(23%) but other aspects were also prominent among the sample, such as economic status (19%).

Intersex respondents from *South-Eastern Europe*, however, highlighted the impact of their economic status: More than half of the respondents found this aspect the most important factor (53%), followed again by a quite high prominence of sexual orientation as well as gender identity and gender expression (each 40%).

Areas of life impacted by Covid-19



When asked to mark areas of their lives where they felt an impact of Covid-19, a majority of all survey respondents chose the area of mental health (67%) and traveling plans (64%), the latter being strongly connected to intersex activism, to be impacted most. Both areas ranked first among respondents of all subregions.

For the total of respondents, the financial situation (41%) and intersex activism (38%), the latter being closely connected to travel plans, were the second most prominent areas, followed by employment situation (32%), health (29%), education (18%), personal safety (11%) and housing situation (5%).

The third and fourth areas of impact, however, showed a difference between sub-regions: 76% of *South-Eastern European* respondents struggled significantly by the impact of the crisis on their financial stability and 59%, more than half, found the impact on their intersex activism substantial. Of the respondents from *Eastern Europe, the Balkans and Central Asia*, however, only 35% considered the impact on their financial situation an important area of impact, followed by intersex activism on the fourth position (26%).

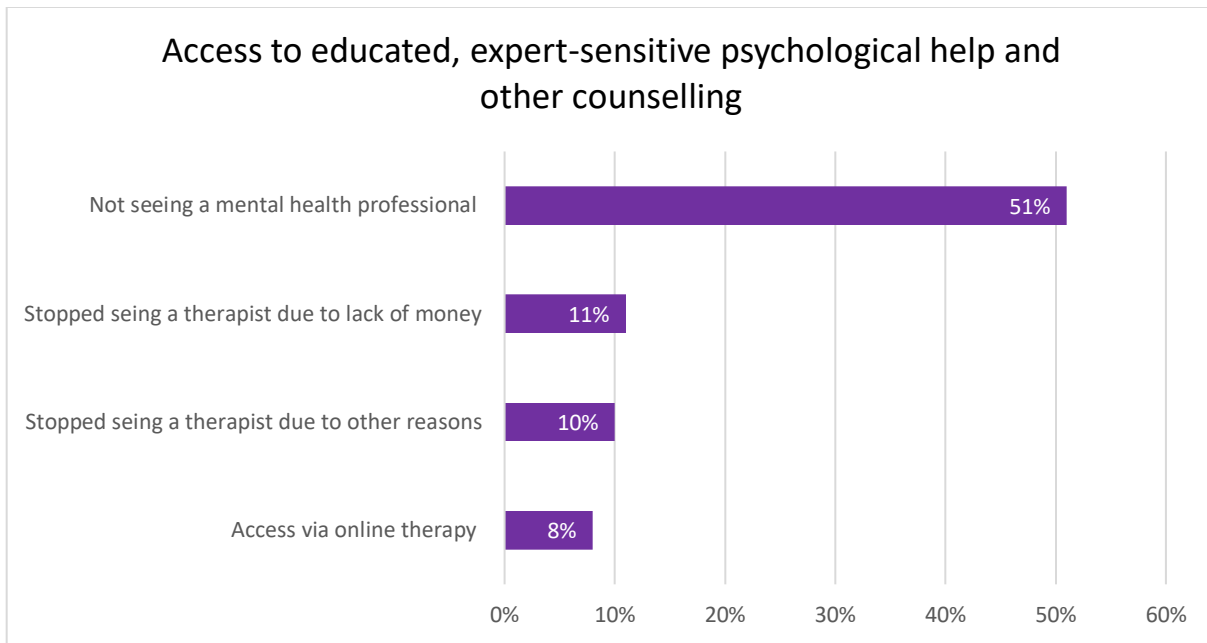
Different to those two sub-regions, for respondents from *Western European and Nordic Countries* the area impact of Covid-19 on the work situation only ranked fourth (33%) but without showing a similar impact on the financial situation as in the other sub-regions (17%). The impact of the pandemic on the area of health ranked third together with the area of intersex activism (each 39%).

While those figures cannot be generalized, the prominence of certain areas, like mental health or the impact on traveling and, for two of the three sub-regions, the economic situation are strikingly similar across all regions. The following sections will show in more detail how critically the pandemic impacts in these areas and will highlight some of the possible reasons.

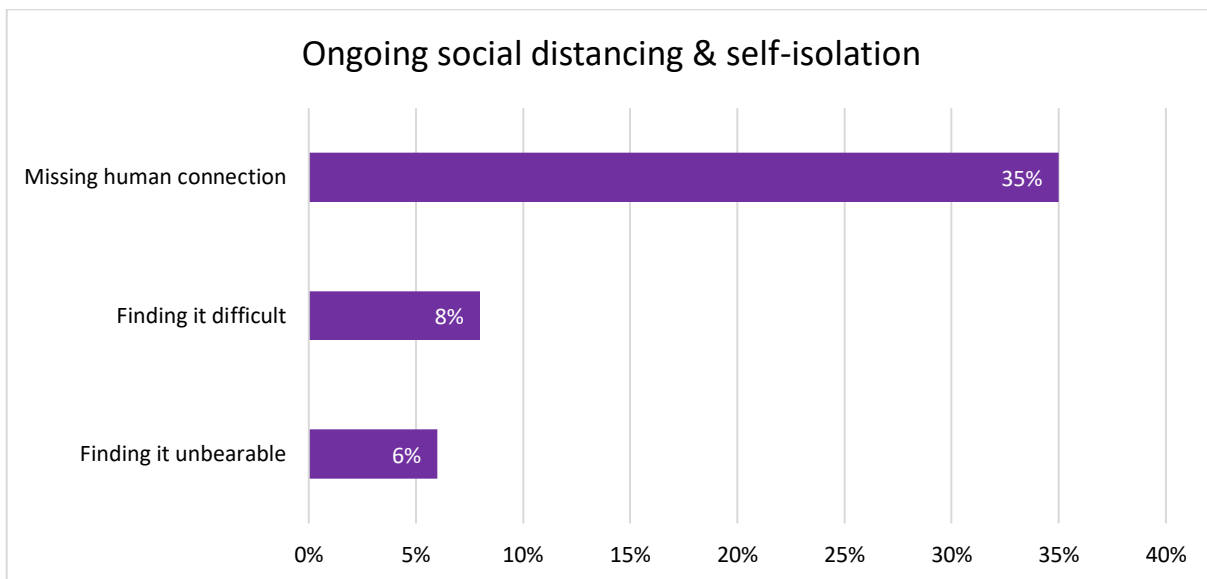
Mental health and Wellbeing

As shown above, the respondents to the survey considered the **negative impact** of the Covid-19 pandemic on their **mental health** and their **well-being** to be the most difficult and pressing issue. 62% of all respondents reported a worsening of their mental health. Of all intersex respondents 11% reported a strong worsening and 8% very strong worsening. Another 43% reported some or a medium worsening. 21% of all intersex respondents are experiencing a relapse of their previous mental health issues due to the pandemic.

The lack of mental health care providers who work with intersex people was already a significant challenge before the crisis and it is now amplified by the pandemic. **Access to educated, expert-sensitive psychological help and other counselling** is highly impaired for intersex people across Europe and Central Asia. 51% of intersex respondents are currently not seeing a mental health professional and 11% reported that, while seeing a therapist before the crisis they had to stop seeing them during the pandemic because of lack of money. 10% reported that they could not continue the visits for other reasons, such as “due to the lockdown”. Only 8% of intersex participants were able to switch to online sessions with their therapist.



At the same time **social distancing and self-isolation** continue to impact intersex people’s and their families’ mental health and wellbeing. Many of the respondents stated that the ongoing social distancing and self-isolation is difficult (18%) or even unbearable (6%) for them and expressed concerns about the “risk of further isolation and deterioration of mental health”. 35% of the survey participants reported missing human connection.



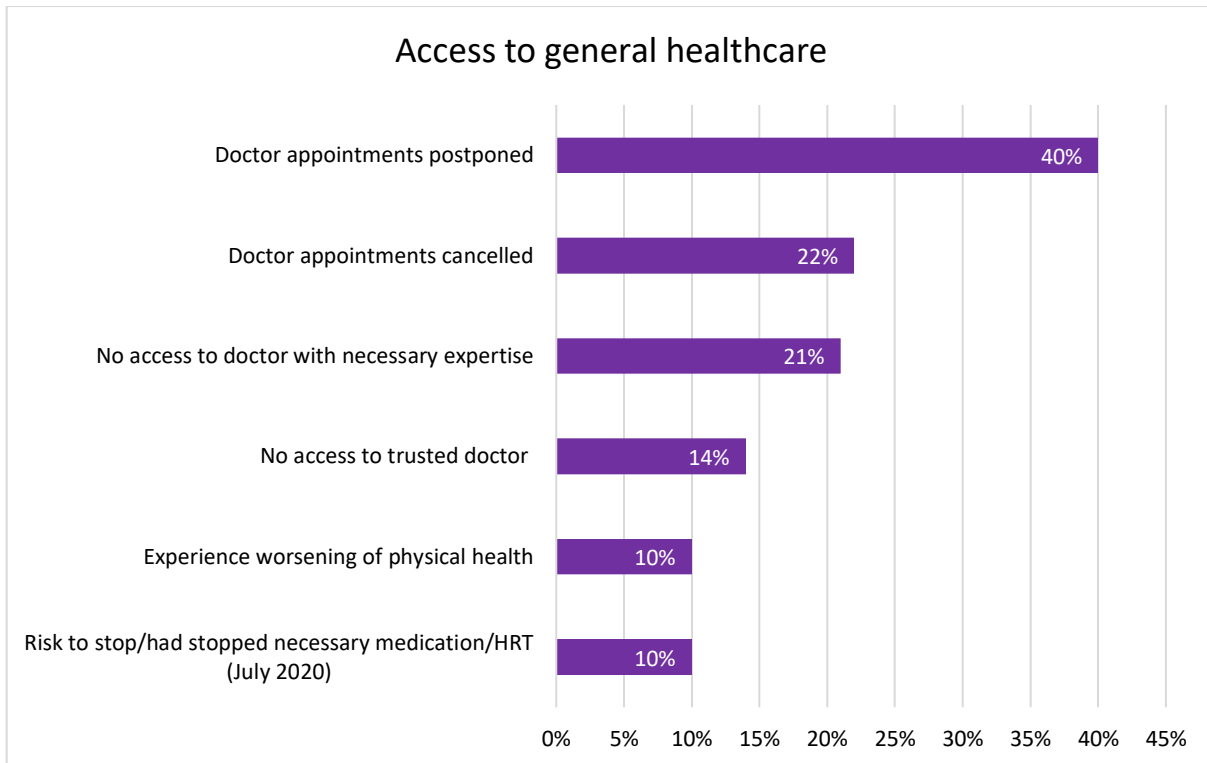
In a few cases, respondents found the restrictions to have some positive impact, as minority stress and the daily life experience of having to be, commute or work in a hostile environment had been reduced by the lockdown restrictions. One survey participant stated:

“The restriction measures and suggested working from home was a greatly positive thing for me. [...] fewer social contacts made it very safe for me and let me find a space outside of minority stress. I hesitate saying the pandemic improved my mental health, but the safety and difference in social contacts did.”
(Western Europe and Nordic Countries)

Health and access to healthcare

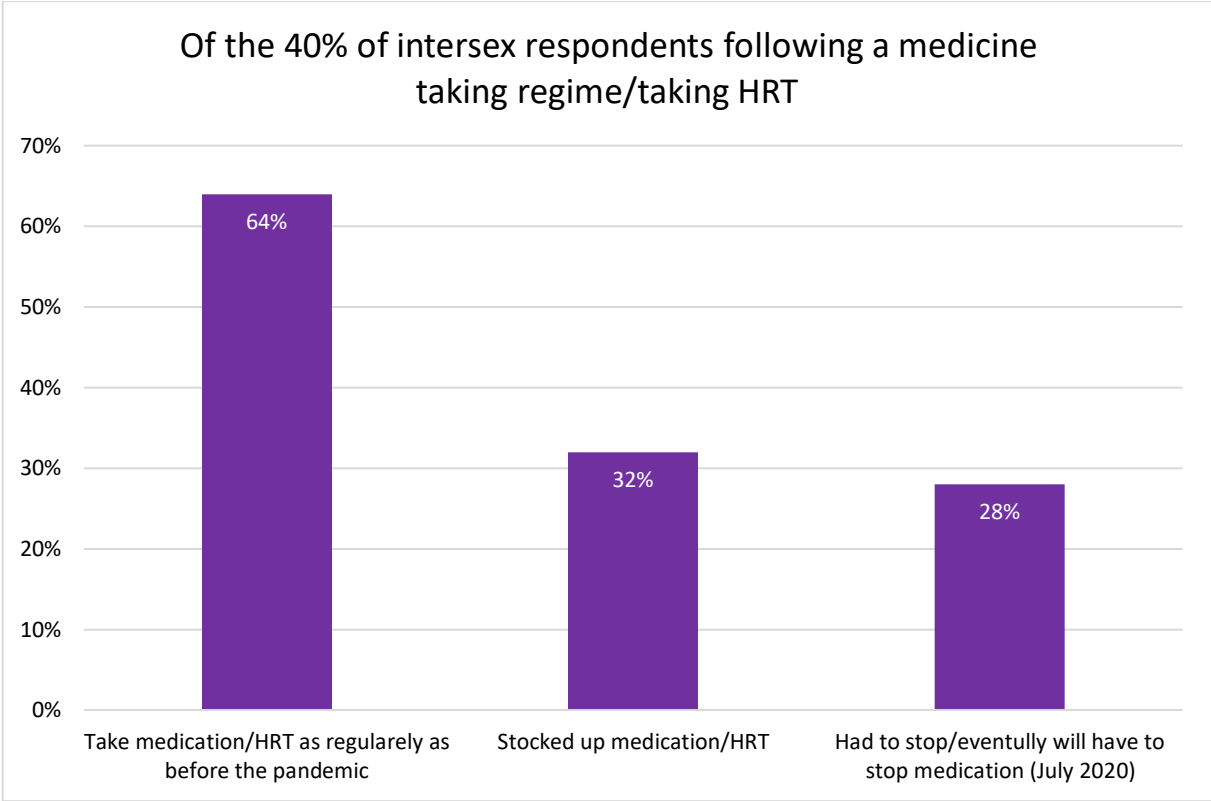
Easy and affordable **access to general healthcare** becomes even more important during a pandemic. Unfortunately, this access is not guaranteed for a substantial part of the survey respondents. 40% of all intersex respondents reported that their doctor appointments were postponed and 22% of all intersex respondents had their appointments cancelled during the crisis.

Restrictions caused by the pandemic lead to unavailability of medical personnel due to lockdowns, cancellations of appointments, reduced office hours or long travel to reach the doctor’s office. This includes, but is not limited to, consultations with a medical professional who is at least to a certain extent educated about the situation and needs of intersex individuals and with whom the intersex person feels safe. 21% of all intersex respondents reported that they don’t have access to a doctor who has the necessary expertise with their intersex body and 14% have currently no access to a doctor that they trust.



The impact on intersex people is aggravated by the challenges faced and the trauma acquired in medical settings. Experiences of disbelief, harassment and violence from healthcare professionals and the lack of knowledge among general practitioners about the existence, let alone the specific health needs, of intersex people have been widely reported as aggravating factors already before Covid-19. Therefore, as many reports to OII Europe in the past years show, seeing a doctor can be a re-traumatising experience for intersex people and the decision to take an appointment can be emotionally demanding. When such an appointment is cancelled or postponed, the ongoing stress of waiting for another appointment can impact significantly on an intersex person's mental health. In addition, a cancellation might put those intersex people, who are in need of treatment, e.g., due to impairments acquired as a result of medical interventions, at risk. Intersex people's problems are amplified during the Covid-19 crisis because they relive their previous trauma through actual contact (or, for good reasons, the fear of having to get in contact) with medical doctors and hospitals.

Many intersex people need to follow a **medicine taking regime or take HRT** (hormone replacement therapy) on a regular basis. This may include, but is not limited to, hormone substitution as a result of surgically induced loss of hormone-producing tissue. 40% of all intersex respondents stated that they follow a regime on regular basis. Of those, only 64% take their medicine as regularly as they did before the pandemic but 28% of intersex people who follow a regime on regular basis reported that they had to stop or will eventually stop taking their medicine. This means that 10% of the total of intersex respondents were at risk to have to stop or already had stopped taking necessary medicine in July 2020.

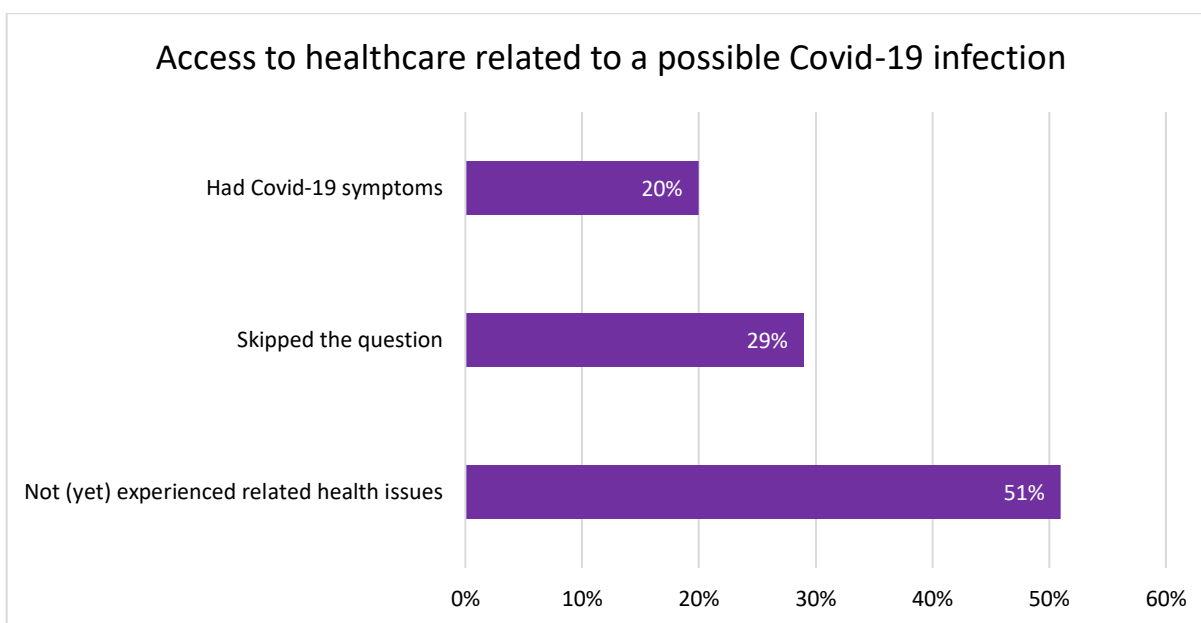


Reasons included the impossibility to renew the prescription due to pandemic-related restrictions, its unavailability in the pharmacies available to them, or lack of money to purchase the medicine. Some respondents pointed out, that limited opening hours and long ways to the doctor's office also cause significant obstacles. One survey participant wrote:

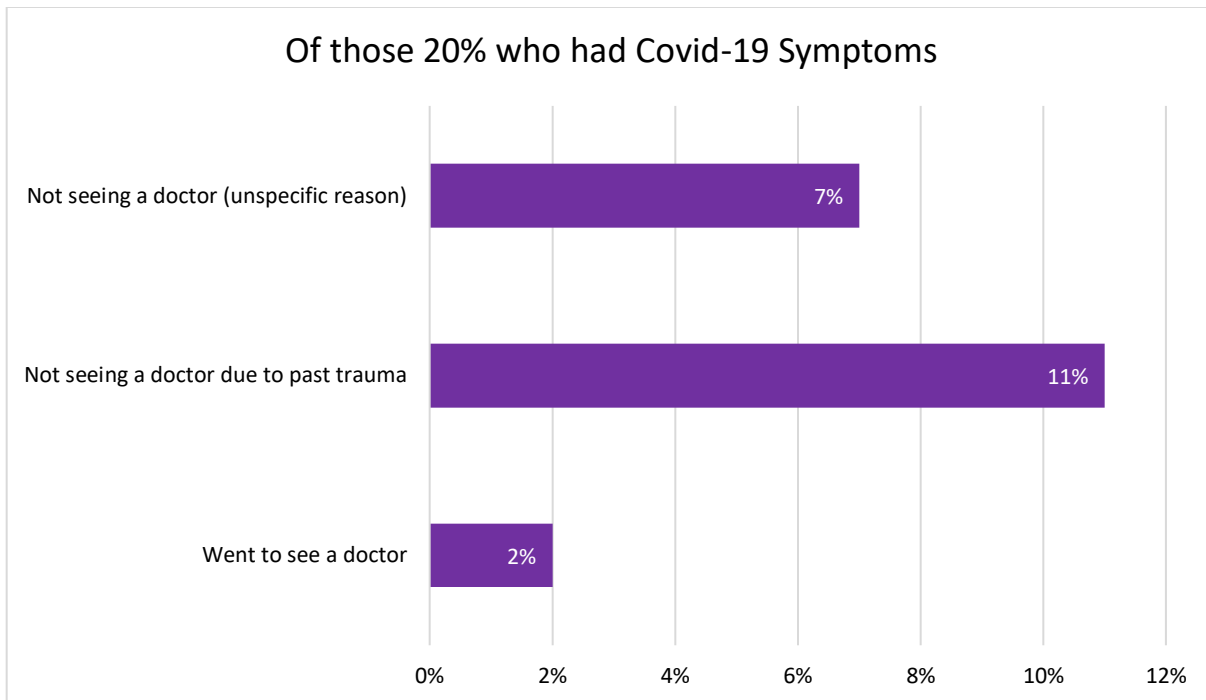
“It [is] more difficult to order and obtain the prescriptions as the doctor's office is far away and at the same time has limited office hours due to Covid-19”. (Western Europe and Nordic Countries)

It is not surprising that 10% of all intersex respondents to this survey stated that they experienced **worsening of their physical health** because they were unable to get medical help. For family members of intersex people, the worry for their intersex child can be significant in times where access to health services is becoming increasingly more difficult.

In regard to **access to healthcare related to a possible Covid-19 infection**, 51% of intersex respondents reported that had not (yet) experienced health issues related to Covid-19.



However, of the 20% who had Covid-19 symptoms only 2% went to see a doctor. 11% stated that they didn't go to a doctor because doctor's appointments are too triggering due to their intersex-related medical trauma. Another 7% didn't see a doctor for other, non-specified reasons.



Some reported that they are afraid of getting Covid-19 as this will force them to enter a medical environment, but also because the access to medical help is impaired by requirements which are not at all related to a Covid-19 infection. In some countries, **intersex individuals with Covid-19 face severe risks to their safety** due to the way the medical care for Covid-19 patients is set up. One participant wrote:

“I’m very afraid of getting COVID-19 because of my medical intersex trauma and the fact that the doctor’s appointments are too triggering for me. The problem is compounded by the fact that in my region Covid-19 patients are registered with a local therapist, and the local therapist does not accept without a minimum medical examination, which includes a gynaecologist or urologist.” (Eastern Europe, the Balkans and Central Asia)

Not only is this coerced examination, which are completely unrelated to Covid-19 symptoms, a violation of the individual’s physical integrity and autonomy – it actively creates obstacles for individuals to access healthcare in times of pandemic.

Travel and Well-Being

Meeting other intersex people, staying in touch with them and peer support has proven to be essential for intersex people’s well-being in the past years. Many of the respondents mentioned “the lack of opportunity to meet in person” and “the lack of knowledge when this situation will come to an end” as very negatively impacting their well-being. In-person meetings with peers who share the same experience and strongly empower each other are vital to intersex activists

and the ongoing work of the intersex movement, as these allow intersex people and their families to be, exchange, build their capacity, and relax in a safe environment.

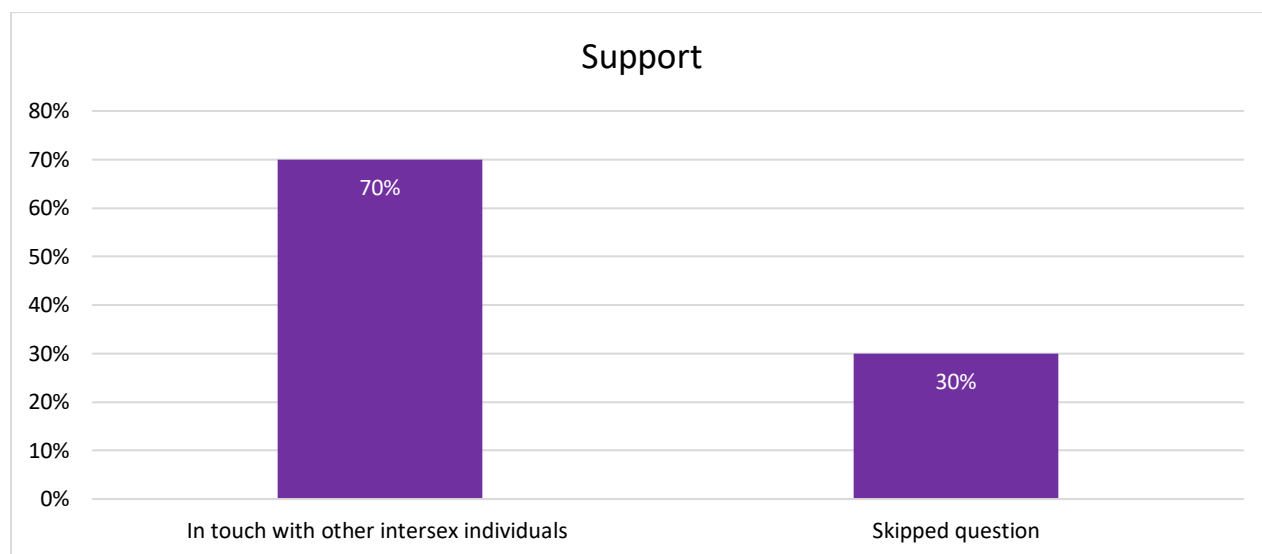
The situation is especially challenging for the many **intersex people who still live in isolated circumstances** and face the ongoing challenge of stigma and taboo in their everyday lives. One survey participant noted:

“Because of the economic crisis, which was a consequence of the pandemic, our company has reduced all vacancies. Therefore, there is no one to replace me on vacation, and I will not have vacation. And on vacation, I wanted to see my friends in the intersex community (we live in different cities) for the first time in my life. But even if it will be possible to take 2-3 days off, it is not known whether in the autumn epidemiological situation will allow us to make long-distance flights without obligatory quarantine.” (Eastern Europe, the Balkans and Central Asia)

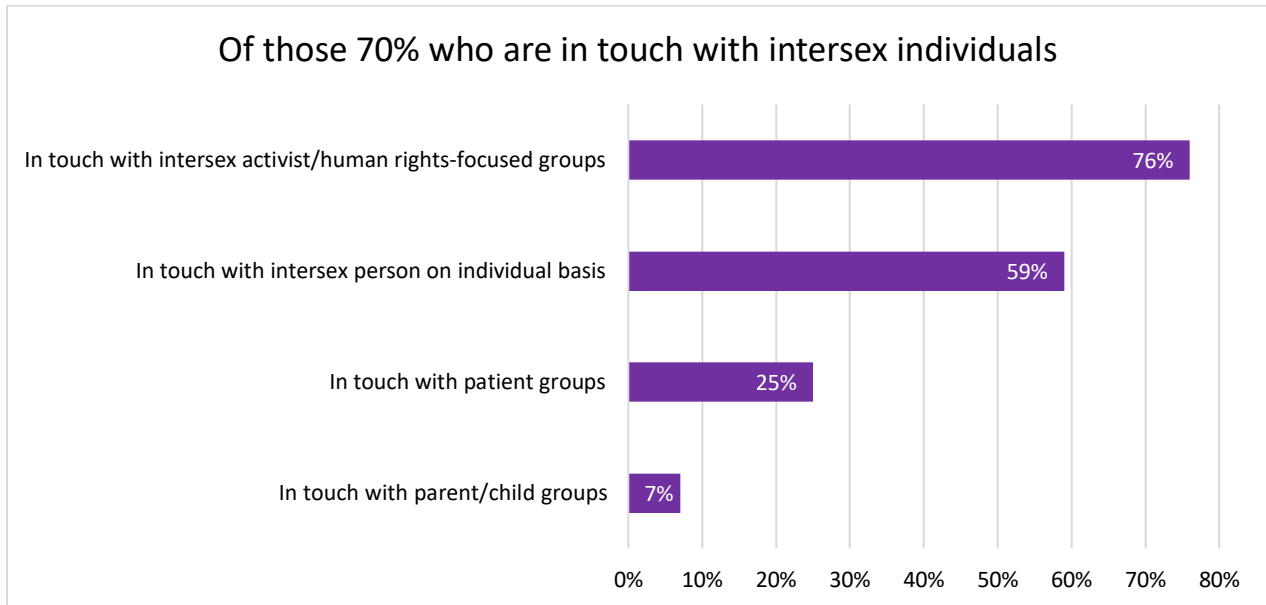
In addition, having to cancel a vacation, while certainly impacting negatively on most people’s well-being, is even more problematic for individuals and families **suffering from minority stress** when their only opportunity to engage in person with others from their minority is cancelled. This is further exaggerated when the individuals are activists with a high level of stress due to the constant exhausting work they do, very often as volunteers and on top of their other obligations. As the survey findings show, 36% of the participants had to cancel a vacation due to travel restrictions, which may have helped them to recover from the daily stress they experience.

Support

Despite the travel restrictions **intersex people** and their families connect with and **support each other**.



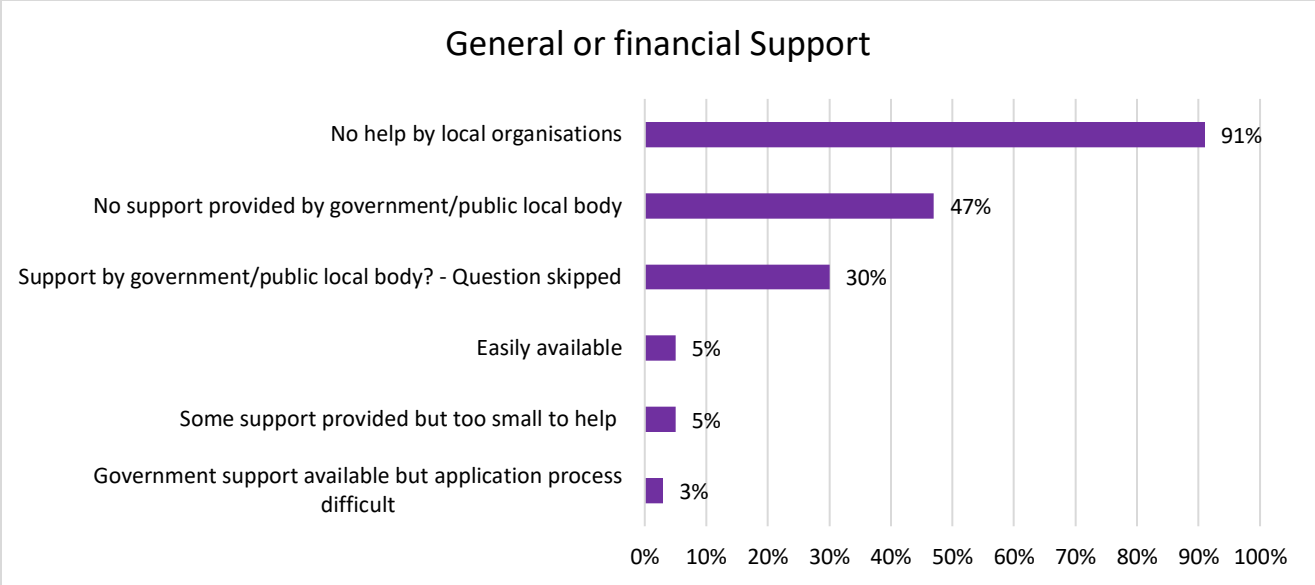
70% of intersex respondents, more than two thirds, are in touch with other intersex individuals. 76% of those respondents stated that they are in touch with intersex activist/human rights-focused groups; 59% reported to be in touch with other intersex person on an individual basis. As examples of means of communication survey participants mentioned Facebook groups, and online meeting tools like Zoom and Skype.



Asked about the frequency of communication and **support from their local/international intersex community** during the pandemic, 17% of the respondents to the survey stated that they are catching up with intersex friends regularly, 33% stated that they are catching up with intersex friends from time to time. Only 8% of the survey participants said that nobody from the intersex community supports them or has reached out to them. Some pointed to the increased loneliness and inability to find support as particularly challenging, especially but not limited to for intersex people who live in rural areas.

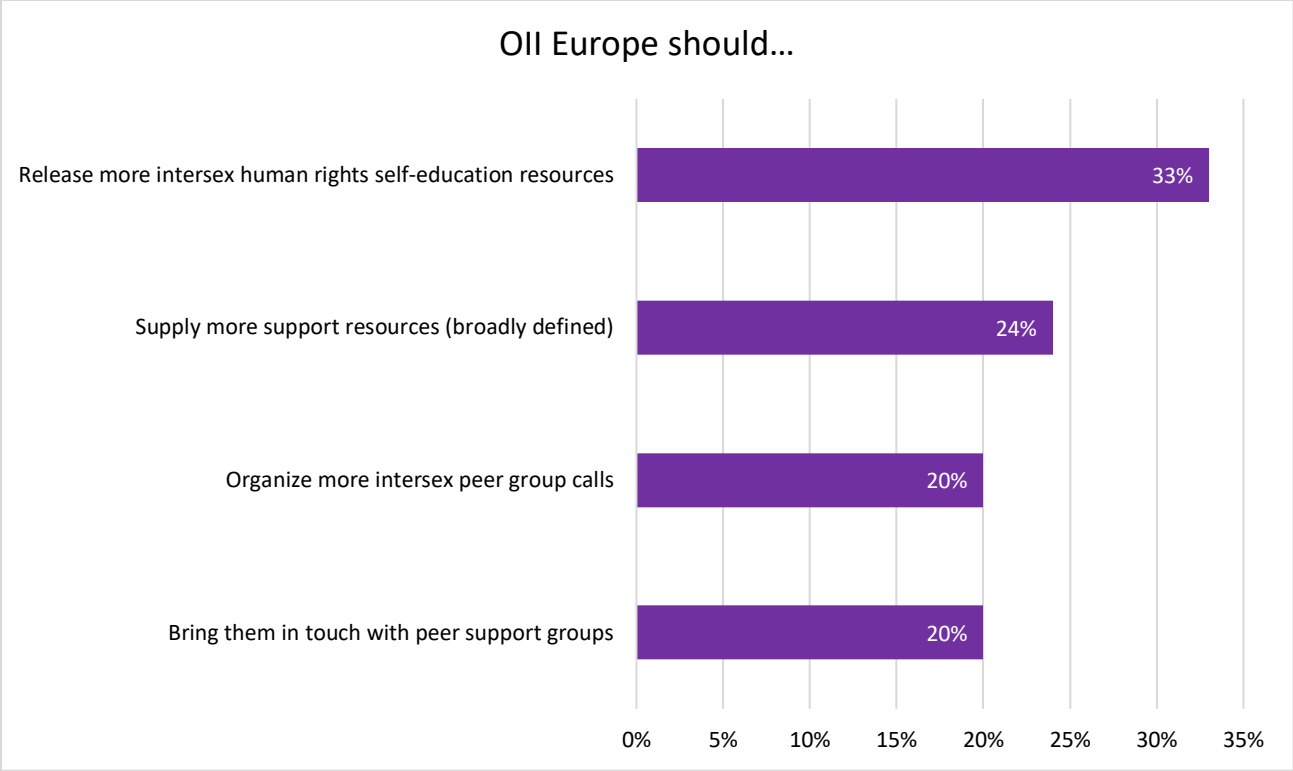
It needs to be noted though that the snowball sampling method likely skews these numbers rather significantly: It's unlikely that intersex people who are not connected to the community heard about the survey in the first place. What these numbers do indicate, however, is that intersex activists and community members who are engaged with the broader European Intersex Community or national human-rights based intersex groups and communities are supported to a very large degree by that community.

When asked about the kind and amount of **general or financial support** they received from **any local organisation**, 91% reported that they didn't get any help. When asked whether their **government or a public local body** provided any financial support, 47% of all respondents to the survey explicitly stated that such a support was not available. Only a few respondents indicated that financial help was available to them at all.



When asked **how OII Europe can support** the respondents and the intersex movement during these difficult times, many respondents highlighted the usefulness of more intersex human rights self-education resources. These findings match the general impression gained in the one-on-one and focus group interviews that priorities should be focused on building their capacity as activists and of using their time as best they can to support intersex individuals and their families in staying strong in times of the pandemic. At the same time, there is also a significant need for more support resources in general (broadly defined), and for an ongoing exchange with other intersex people, e.g., through intersex peer group calls, like the weekly virtual campfire which OII Europe has offered since the beginning of the pandemic, or intersex peer support groups. For intersex children, the isolation, while generally aggravated by social distancing and lockdowns, has multiple facets. Even more than intersex adults, who have more opportunities to reach out to other intersex adults, intersex children miss contact with other intersex individuals, intersex children specifically, a situation that does not stem from the pandemic alone. One child suggested that

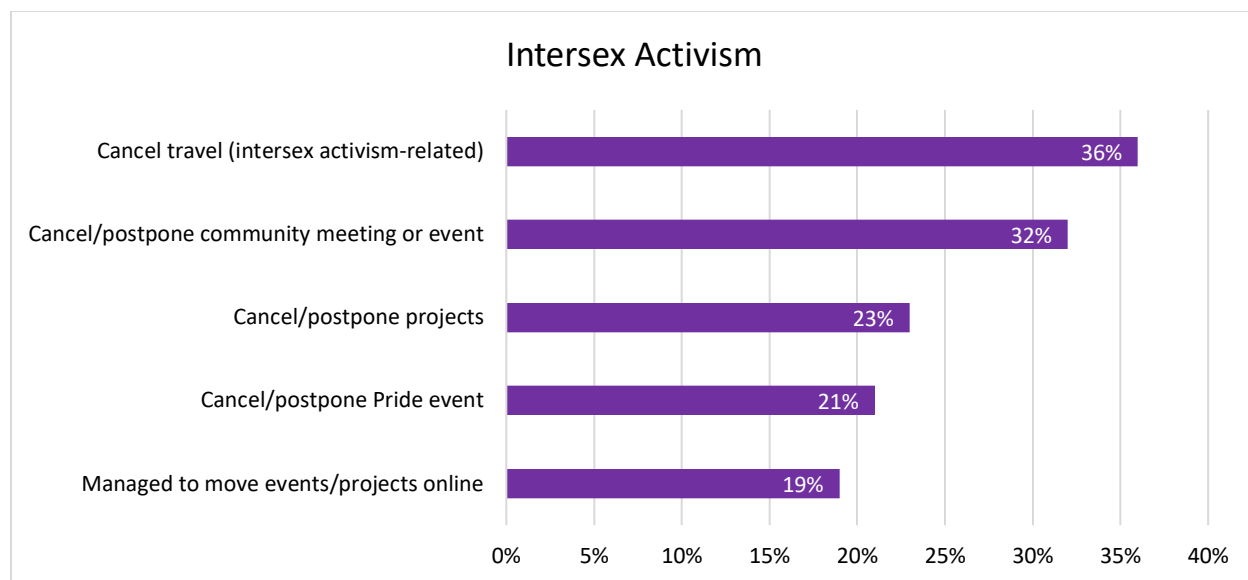
“OII Europe could make a list of intersex children (12-18 years old) so that we can correspond to intersex children in English”. (South-Eastern Europe)



Intersex Activism

Personal, face-to-face connection has been key to the emergence of intersex communities on national and regional levels. In the early 2000s, while emerging online communication was an important means for intersex people to reach out and connect when there was no possibility to meet in-person, the movement started to grow rapidly when intersex activists from all regions of the world met for the first time during the 1st International Intersex Forum in 2011. The same trend emerged for the European Intersex Movements, whose growth is clearly tied to opportunities to meet in person, such as the OII Europe Community Event & Conference or pre-meetings to the ILGA-Europe annual conferences.

Against this background, travel restrictions and other restrictions induced by the pandemic have a multidimensional impact on intersex people and their families. In addition to the significant impact on their wellbeing (see *Travel and Well-Being*) they impact negatively on intersex activism, e.g., through the need to cancel travel related to the intersex activism, cancellation or postponements of intersex community meetings or events or projects, only some of which can be changed to an online format.



In addition to the external restrictions, the majority of respondents were worried about the ongoing negative impact of isolation and reduced in-person contact and how these would further impact on their mental and physical health, including worries that these would lead to a **reduction of capacity to continue intersex activism**, both at the personal and movement levels. These worries were expressed across all sub-regions.

Other participants pointed to the risk carried by moving activism to a digital environment and the lack of personal interaction, especially in regards to a **reduced capacity for community building**. As one respondent wrote:

“The pandemic slows down our plans and actions, especially our reaching out to new people and community building. It also reduces our opportunities to meet politicians and professionals, and to lecture and travel. If that doesn’t change most of the activities will be online, which may not be as effective.” (Eastern Europe, the Balkans and Central Asia)

Other concerns expressed were related to **limited monitoring capacity** and a negative impact on the respondents’ advocacy work. As one participant noted:

“Monitoring medical gender determining interventions has become much more difficult with the pandemic, due to the limited personal contact”. (Western Europe and Nordic Countries)

Limits in terms of awareness raising were another area of concern for many of the respondents. The decrease of opportunities to raise awareness with the general public, together with the impact of the “new normal” of social distancing were seen as critical factors – during the pandemic but also in the long run. As one respondent explained:

“It will be more difficult to inform people about intersex existence and to work on visibility. Fear and social distancing make it hard and it will be worse.” (Eastern Europe, the Balkans and Central Asia)

Another participant pointed to the general decrease in empathy and of willingness to be aware of the needs of vulnerable minorities:

“[The] pandemic is pushing intersex people more on margins and work on the understanding of intersex phenomena and empathy for intersex people will be harder.” (Eastern Europe, the Balkans and Central Asia)

Other respondents highlighted possible consequences of ongoing social distancing and lockdowns that make many forms of awareness raising impossible, except for those which are based on online communication and significantly narrow the outreach to diverse groups of the population. One respondent stated:

“Less projects and events, less visibility.” (South Eastern Europe)

Many respondents spoke about the problematic link between **lack of funding** and, as a result, the strong reliance on volunteer activism, which is becoming **even more difficult during times of a pandemic**. Many respondents pointed to the increased need to prioritise personal life against activism:

“When people are afraid for their health, they do not participate in activism with a physical presence and it is more difficult to trust the activists, that is, I am afraid that activism and rights take second place for many people.” (South Eastern Europe)

One participant wrote:

“Most of us use spare time for this work. In time of pandemic, we are facing new challenges (which are not specific to intersex, but generally). I am worried that as economic situation becomes worse and people lose jobs and their financial security is threatened the priorities will shift to survival mode and many activists will shift their attention from activism to looking for a new job, paid work will take even bigger priority. This can be compounded if people are having caring responsibilities and / or health issues. Of course, it also depends on us to say clearly in grant applications that we want to compensate people or at least some people for their work, but with so few funds available and resources being so precious this is not on the top of the agenda. It would be regrettable if we lose the momentum because of that.” (Western Europe and Nordic Countries)

The “new normal” requires specific tools and financial means that are not equally available to everybody. As one participant wrote: “It will be even harder because you have to have the time, the IT tools and the financial means to be able to campaign. We are all in burnout. It is almost impossible to find a room to meet. It takes us more time and energy to coordinate and campaign. You have to fill out endless forms for calls for projects for a ridiculous budget. If we received structural subsidies, it would save me the energy devoted to applying for subsidies.”

Regarding the challenges caused by the negative economic impact of the pandemic and isolation to their activism, respondents across all sub-regions expressed concerns about **governments** who use the pandemic to (further) **restrict human rights work**. Respondents

from the *Eastern Europe, the Balkans and Central Asia* region highlighted the “illegal detention of citizens” and the “prohibition of freedom of movement without the establishment of an emergency regime”. Respondents from *South-Eastern Europe* equally reported an unprecedented increase of breaches of fundamental rights. One respondent stated:

“With justification for the pandemic, my government has tried and is trying to minimize my right to express opposition to the measures it is taking, minimizing my right to react with police violence - unprecedented - for a European country.”
(*South-Eastern Europe*)

Respondents from *Western Europe and Nordic Countries* expressed similar worries and equally see a risk in governments using the crisis to undermine fundamental rights. One of the participants from this region stated:

“At the political level, I fear a rise of the extreme right, totalitarianism, more security, more conservatism, protectionism. [There will be] more and more precarious people.” (*Western Europe and Nordic Countries*)

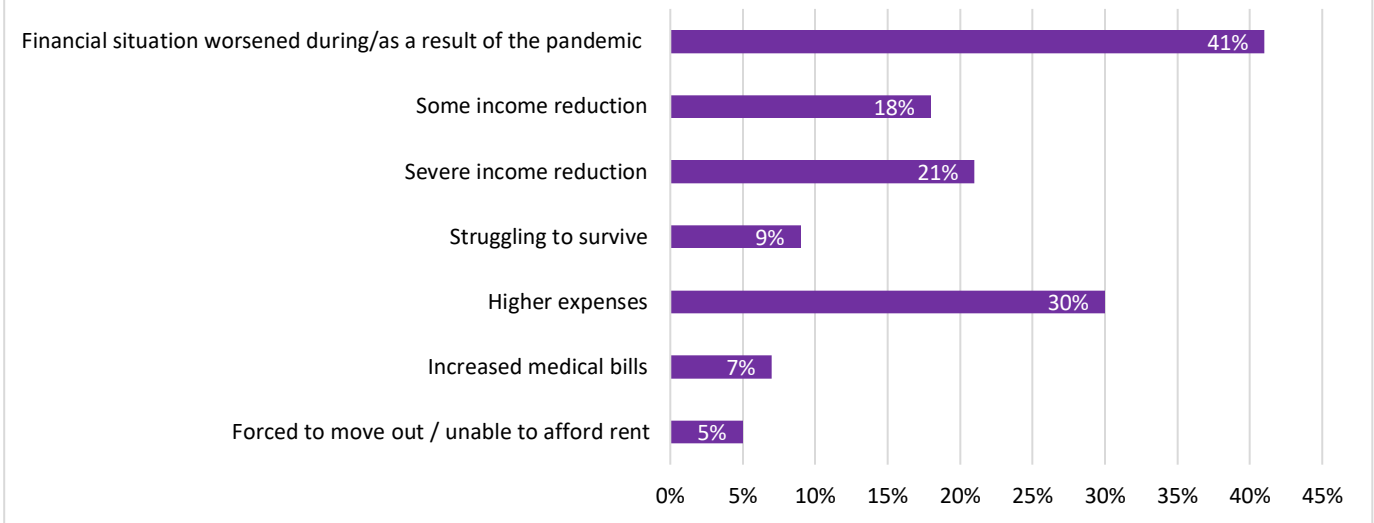
Financial and Housing Situation

The pandemic is impacting on many people’s economic situation and financial stability across the globe. Intersex people and their families are no exception. In fact, as the FRA LGBTI Survey II showed, intersex people are among the most vulnerable group in regards to their financial and work situation: 51% of intersex respondents of the 2019 FRA LGBTI Survey II confirmed that their household’s total income makes making ends meet difficult and of the 29% of intersex respondents stating that they experienced housing difficulties, 37% said that this happened due to financial problems and insufficient income.⁵

The findings of the OII Europe Covid-19 survey show that the situation may have been aggravated during the pandemic: 41% of all survey respondents stated that their financial situation has become worse during and as a result of the pandemic. 21% reported experiencing severe income reduction, almost half of which are **struggling to survive**. Furthermore, 30% of the survey participants stated that they **have to spend more money** during the pandemic than they usually do, including for **increased medical bills** and some stated that they **had to move out** because they were not able to afford their rent anymore due to the pandemic. Some participants reported that they had to move back in with their families due to the loss of income.

⁵ See OII Europe (2020): Infographic - Intersex people in Europe face housing and economic difficulties <https://oieurope.org/housing-and-economic-difficulties/> findings collected from the European Union Agency for Fundamental Rights (FRA): LGBTI Survey Data Explorer <https://fra.europa.eu/en/data-and-maps/2020/lgbti-survey-data-explorer>

Finance and Housing

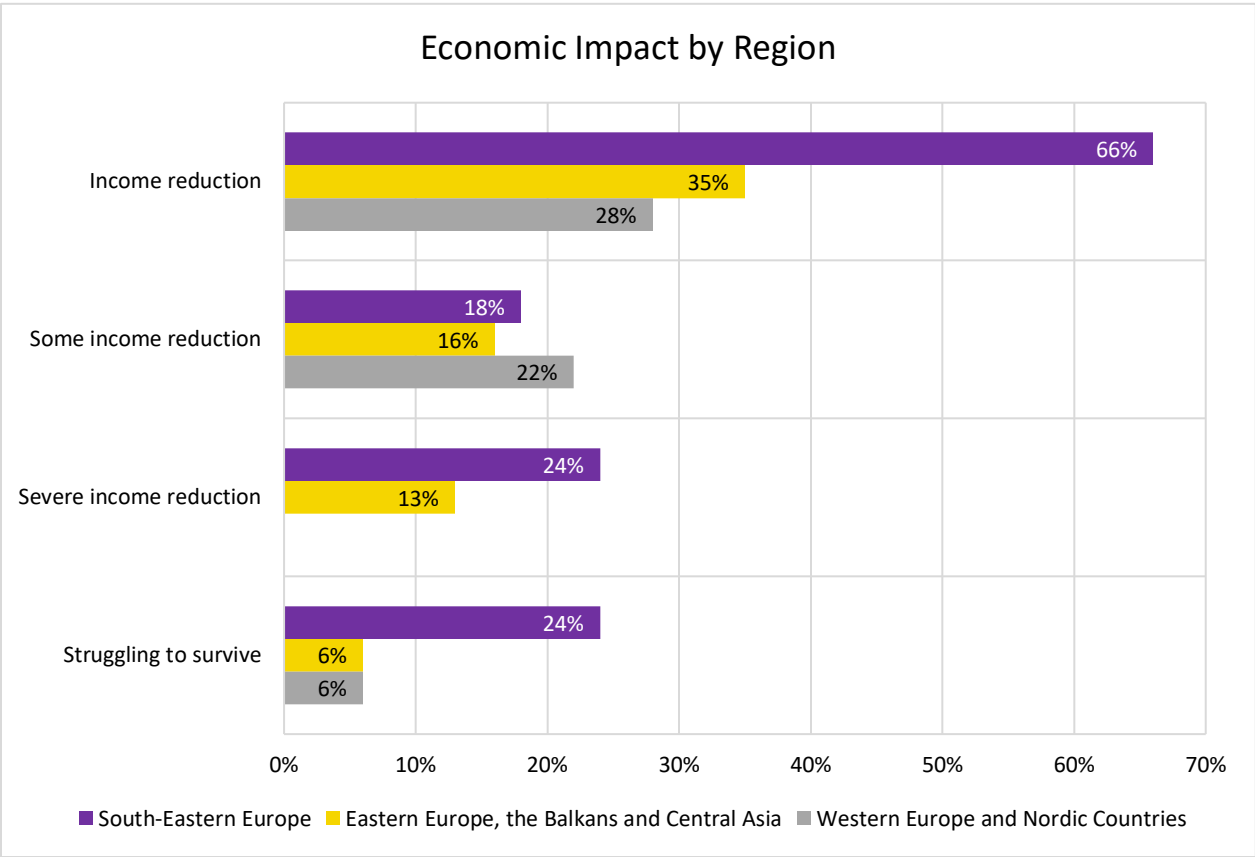


Many respondents across the sub-regions reported that prices have gone up during the pandemic, including prices for bare necessities as well as incidental expenses. A participant from *Western Europe and Nordic Countries* noted that they have to “spend more on food because I avoid the discounters [these places are further away]” and another respondent from *South-Eastern Europe* mentioned that they had “increased bills for the regular expenses of the house due to a pandemic”.

Some participants explained that they were now struggling even more with finding a job due to the pandemic. A respondent explained how they had to spend money to keep their job:

“When I went to work, I had to pay for PCR analysis for coronavirus [and] the prices of groceries in stores have risen significantly.” (Eastern Europe, the Balkans and Central Asia)

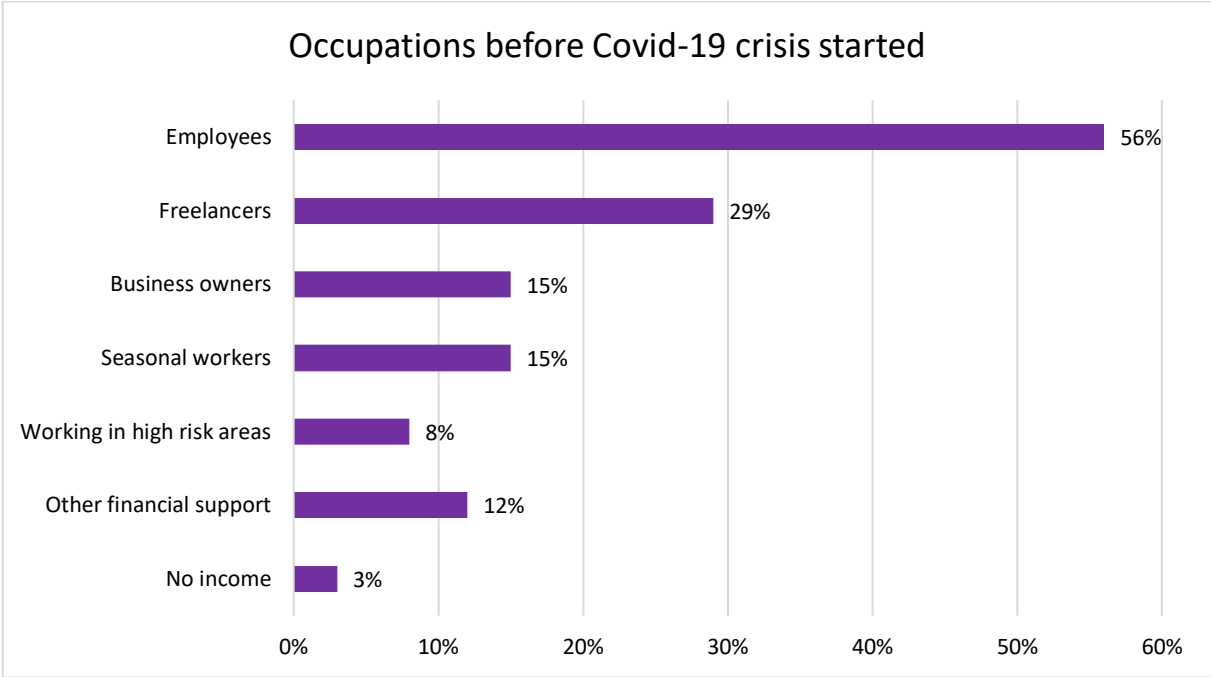
Only a few respondents reported that they spend less money, for example on public transport or because they didn’t engage in recreational activities due to the lockdowns.



Respondents from *South-Eastern Europe* reported the heaviest impact on their financial situation: overall 66% stated that the pandemic has led to income reduction, with 24% reporting that they are experiencing a severe income reduction. For another 24% of respondents from this region the economic crisis as impacted so strongly on them that they are struggling to survive.

The economic situation of intersex respondents in the other two sub-regions has aggravated too, but to a lesser extent: 35% of survey participants from *Eastern Europe, the Balkans and Central Asia* reported a decrease of their financial capacity. While 13% of all respondents from this region reported that they are experiencing a severe income reduction 6% said that they are struggling to survive as a result of the economic crisis. Among survey participants from *Western Europe and Nordic Countries*, a total of 28% are affected by income reduction; for most respondents (22%), however, the situation is bearable. Still 6% are struggling to survive due to severe income reduction.

Economic Impact by Occupation⁶

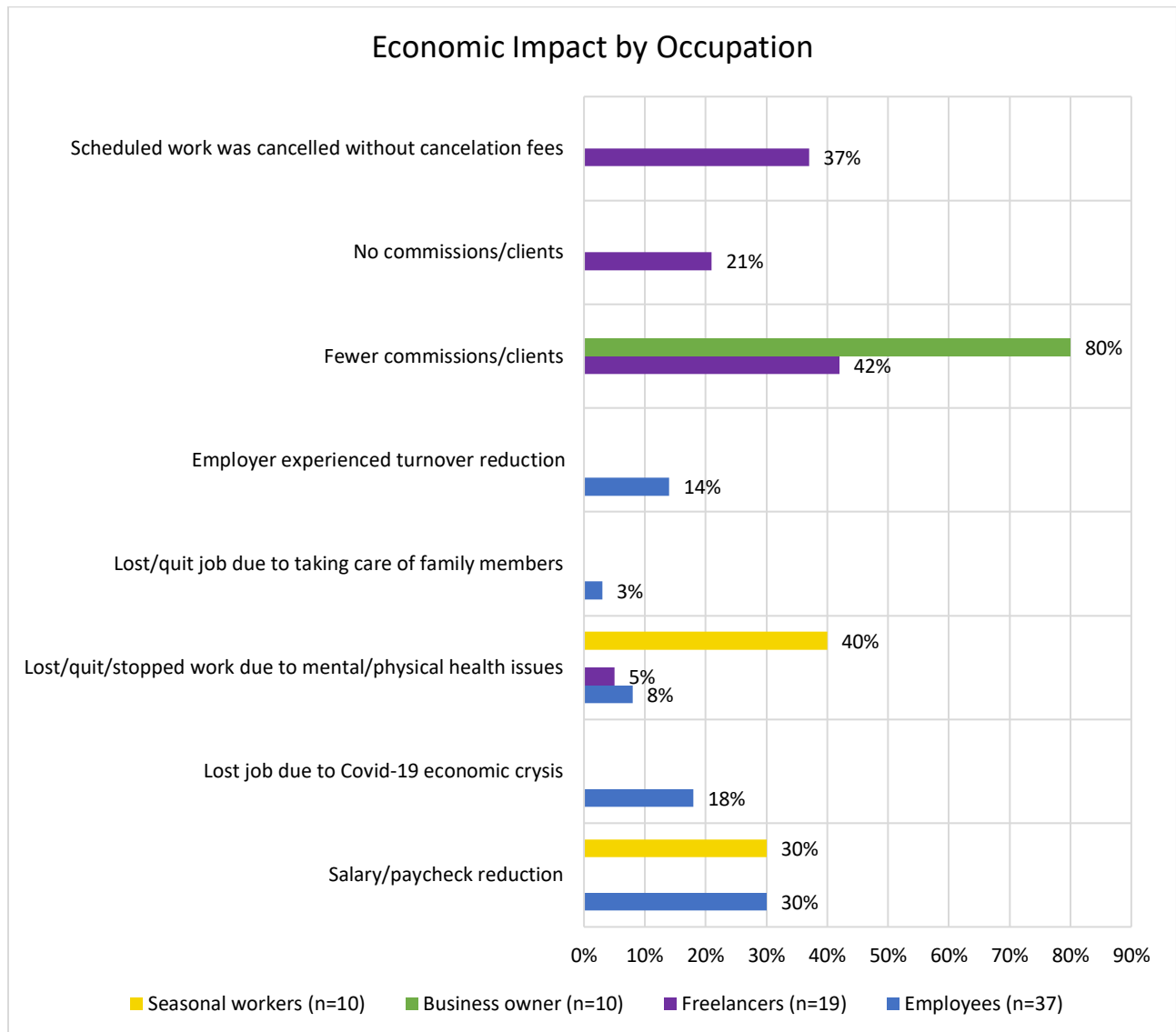


Asked whether their country's **government or any public body provides financial Covid-19 response support**, 47% of the total participants said no (32% skipped the question). Only 4% said that this option is available and easy to access, while another 4% said that funds were available the amount was so small that it did not help much, and 3% stated that despite the option being available the application process was difficult. Another 9% reported different ways of indirect financial support, e.g., through loans or wage subsidies given by the government but some also pointed out that they did not necessarily fall under the group of people getting that support.

Some participants reported that the support was limited to “only for parents of small children or some business owners”, another said that they didn’t “fall into the category of citizens who are receiving assistance in my country” or that the support was unavailable to them. Only three participants (5%) reported that they were, as employees, benefitting from governmental measures, like e.g., interest-free loans to “pay salaries for organizations in the industries most affected by the pandemic” or got a deposit or check from their government as a form of support.

⁶ Some respondents detailed their occupation further in the comments, e.g., as apprentice or as long-term unemployed and finding work in community service programs for only a few months. Some respondents have more than one occupation (e.g., they may be employed and work on freelance contracts at the same time). Those respondents were able to give information about the situation in different fields of work.

Situation by field of occupation



Some of the respondents (n=3) work in a field with a high risk of societal stigmatisation which adds to their vulnerability. All of them were strongly affected by the economic impact of the pandemic: Two of them reported an income reduction due to the pandemic and one has lost their job as a result of the pandemic. While these numbers cannot be generalised, they still are in line with general observations on the increased risk for stigmatised groups in times of crisis. Another 8 respondents' income stems from a state pension, social welfare or other financial support through public and governmental bodies. Two of them reported a reduction of this financial support and one respondent reported getting no support anymore due to the pandemic.

Education

Education around the world has changed since the Covid-19 crisis. Among the survey participants, 35% were engaging in a form of educational curriculum before the pandemic. Of these respondents, 52% experienced that their lessons were **moved to an online format**. Moreover, of respondents who had been enrolled in an educational curriculum or training before the pandemic had to **quit** their education **for financial reasons** (22%) or **mental health reasons** (13%).

Some respondents found that the new format added new positive features to their education. One participant wrote:

“I attended educational [online] meetings as part of my postgraduate studies and I can say that it was a positive enough experience. I also attended some medical lectures, which when done through a platform [where] we had the right to interact with the speakers, which is very positive and rewarding.” (South-Eastern Europe)

They also pointed out that this increased access could also have a positive impact on school children’s education, if set up appropriately. Another participant wrote:

“Wonderful experience. Good connection. But it's not a replacement for real communication.” (Eastern Europe, the Balkans and Central Asia)

Internet Access

Having access to participate in the “new normal” in times of Covid-19 strongly depends on a person’s access to the Internet and the availability of hardware and software equipment which allows attending video conferences and online meetings. The economic challenges intersex people often face create additional challenges in regards to their capacity to engage via these means.

While many respondents skipped the question (40%) which in this case likely indicates that it has no relevance for them, 12% of the respondents to the questionnaire reported that they have access but that it is costly and affects them financially, and 6% said that they only sometimes have internet access.

In addition, the impact of video meetings and constant screen-work even for team meetings can have a detrimental effect on an individuals’ health: 18% of all respondents reported that using the Internet is impacting negatively on their health due to the amount of screen time.

Many survey participants described their experience with the new “digital normal” as tiring and as mentally and physically exhausting, regardless of whether they considered the increased digital communication as being overall beneficial or not. One participant wrote:

“Video conferencing brings several people together in different places and these people previously would not have been able to participate in meetings. It is therefore positive. However, these meetings are very tiring... Video conferences are often shorter than face-to-face meetings. The sound quality is different depending on the connection speed. Not always easy on a smartphone.” (South-Eastern Europe)

Some found that the digital format prevented them from participating like they would in an in-person environment as they found the online communication “difficult” and, as one participant wrote, “embarrassing, so I kept it to a minimum/voice only”. Others mentioned how technical issues create communication challenges, such as “connection problems in meetings can be annoying and make people unable to interact”. Some pointed to the risk of getting connected so easily, just with a click, and stated that it is “very useful but also exhausting. Partly because you take fewer breaks between meetings. It’s that simple: one click, and you’re connected”. Others noticed that “being in an online gathering drains energy more quickly” and other concluded that while “it has been a good way to proceed with many issues” they needed to have live interaction.

Safety

The Covid-19 crisis not only restricts individuals’ in their daily life but also leads to a higher risk of getting stuck in a risky and unsafe environment. While 78% of the intersex respondents reported no negative impact of the pandemic on their personal safety or had skipped the question, 11% stated that they are **staying at home** in self-isolation **with someone whom they have a strained relationship** or other difficulties with, including some respondents who reported experiencing violence, abuse, harassment by a person they are currently forced to live with. Another 11% expressed feeling unsafe for different reasons.

While only one person reported experiencing violence, abuse or harassment on the street, many commented about how the crisis has increased the stress level in the general population and, as a result, their feeling of not being safe – on the streets but also in medical facilities. One respondent noted:

“I’m scared to get sick because the hospitals are overloaded and the doctors are working hard. There’s a lot of aggressive people around. We work in the office despite the pandemic and there’s a risk of getting sick. I have chronic diseases and there’s a good chance that I’ll feel terrible if I do get sick.” (Eastern Europe, the Balkans and Central Asia)

Others reported that, despite being fully supportive of the need to wear a mask, seeing people with masks, especially those wearing medical masks, was **triggering their medical intersex trauma**. At the same time many intersex people are part of risk groups, including as result of impairments of their physical health acquired through unnecessary medical interventions. The comparably high number of people who refuse wearing a mask or do not wear it properly potentially puts intersex people at risk. As one respondent described:

“The situation on the street is difficult because of the high level of ignorance of people who do not understand why one should wear a mask; medical masks have trigger factor.” (Western Europe and Nordic Countries)

When asked about the situation in their country or region, many respondents expressed strong concerns about the political developments during the pandemic, including an **increase of political and societal attacks** on vulnerable minorities during the pandemic. As one participant from stated:

“The government and religious authorities began to constantly call for attacks on LGBTI+ individuals. This increased even more in the Covid-19 period. The situation is getting worse for LGBTI+ individuals in [my country].” (South-Eastern Europe)

The Future

Survey participants were asked how they envision their life one year after the survey (i.e., July 2021) and how they thought their situation would look by then. Only 6% thought that everything would be back to times before the pandemic, but 50% of the survey participants were convinced that the situation would be better, even if some restrictions and protective measures would still be in place. 10%, however, stated that the pandemic would still be ongoing and be approximately on the same level as it was in July 2020 and 5% thought that it would be much worse.

In the blank text box to this question, many respondents stated that they **felt very unsure and insecure about their personal future** as they expect to see limitations carrying on even after a decline of the pandemic and for life to become “harder and more limited” and increasingly difficult “due to poor finances and isolation in a small place”.

Respondents highlighted specific areas of concern, with **concerns about their (future) health and financial situation** being most prominent on a personal level. As many intersex people suffer already from health issues due to unnecessary medical treatment and many already faced severe hardship making their living, there is a high risk that these worries will become reality.

While often being part of a health risk group due to the medical interventions they were subjected to, intersex people often “go unnoticed in medical procedures”, unless they choose “to open selectively to doctors regarding the intersex part”, as one participant pointed out. As the latter is often connected to trauma and experiences of harassment by medical professionals and access to trustworthy doctors is even more limited during the pandemic, many intersex people may not be able to benefit from the priority given to risk groups.

Therefore, **lack of access to a future vaccine** was another concern expressed by the respondents. When asked about whether they thought that a vaccine would be available to

them, of the 50% who responded to that question only 72% said they were sure to get access to a vaccine, 8% said they didn't believe to get access and 20% were uncertain. Across all represented sub-regions, respondents mentioned a person's profession, class, income and whether they live in a city or a rural area as being as critical factors for accessing a vaccine. One participant wrote:

“It will depend on their social status. Intersex people from high-risk groups (pensioners, medical workers, civil servants) are likely to be vaccinated free of charge - at the expense of the state. Everyone else will have to rely on paid vaccination. The cost of the vaccine is likely to be high. City residents will be able to afford it, but it is unlikely for rural residents, young people from large families working in low-paid jobs.” (Eastern Europe, the Balkans and Central Asia)

Another participant pointed out:

“Like for the rest of the population, it will depend on places and social classes”. Respondents from South-Eastern Europe came to a similar conclusion: “I think in general it will be [...] too late to become accessible to everyone. Therefore, intersex people will not easily access it.” (Western Europe and Nordic Countries)

Apart from concerns about their personal future many respondents, however, were also extremely concerned about the pandemic's **impact on society** in general and on **intersex activism**. Several respondents were worried that some changes might be more permanent, including an increase of aggressive behaviour in society due to the economic and social impact of the pandemic, which would make life even more difficult for all vulnerable groups, including intersex people and their families (see *The Baseline – Intersex realities before the Covid-19 pandemic*). Based on their observations since the beginning of the pandemic, some explained their concern about a **further increase of aggression and extremism** but also saw the chance for more positive change:

“At the political level, I fear a rise of the extreme right, totalitarianism, more security, more conservatism, protectionism. [...] more and more precarious people. On the other hand, I hope for more ecology, respect for the environment, more respect for others, more attention for social security.” (Western Europe and Nordic Countries)

Other respondents ended their observations on a positive note and mentioned **possible positive future outcomes** of the current “new normal” related to a more diverse set of means and tools of communication in general and a bigger acceptance of these tools throughout society and working environment in the future:

“[A] more hybrid situation, where we don't have to travel around every time, we want to have a meeting, while at the same time having the option to meet in person. Also, in relation to work... working from home will be more normal, avoiding travel time and an overall better work/life balance.” (Western Europe and Nordic Countries)

Conclusion

Overall, the survey findings show that the Covid-19 pandemic had and continues to have a **massive impact on all areas of lives of intersex people** with the negative impact in the area of mental health, general access to healthcare and on intersex people's and their families work and financial situation being the most prominent.

Medical trauma, acquired through unconsented, non-necessary medical interventions and treatment impact strongly on intersex people in this pandemic: *Intersex people's problems are amplified during the Covid-19 crisis because they relive their previous trauma through actual contact or being at risk to be in contact with medical doctors and hospitals, aggravated because the societal and medical environments do not account for their trauma.*

Regarding the pandemic's impact on financial situations, many intersex people are experiencing financial problems and/or income reduction as a result of the pandemic, with about half noticing that they have to spend more money during the pandemic. Some survey participants lost their job due to the economic crisis or had to quit their job because of their mental or physical health issues related to the Covid-19 pandemic, with a few facing severe housing problems as a result of their financial situation. Several participants of the survey are staying at home in self-isolation with someone whom they have a strained relationship or other difficulties with.

On a less personal level, the pandemic is severely impacting intersex activism and there is a high risk that the situation will aggravate with each month the crisis continues. The pandemic is preventing intersex activists from using in-person methods of building community, raising awareness and advocating for intersex human rights that they have created. With an extremely high amount of volunteer work still at the core of intersex activism, the need of many intersex activists to refocus their energy on their personal financial survival directly impacts the capacity of the movement to work towards intersex people's rights in Europe and Central Asia. For many of those who continue their work, the new digital normal brings an additional factor of stress that can be detrimental to their health in the long run, such as the tiredness and exhaustion induced by online meetings, especially if these need to be taken after already long working days in a digital-only environment. Others may be prevented from fully engaging in the new digital normal as a result of the lack of financial capacity to get the necessary technical means.

On a positive note, the majority of respondents were in touch with other intersex individuals and intersex organisations and groups on a regular basis. While on one hand this can be considered as a result rooted in how the self-selection of respondents took place, it stills shows that the bond intersex people have built in the past few years and the intersex movement in Europe and, just recently Central Asia, is strong enough to hold even when faced with a crisis. This is not guaranteed in all movements, especially not with a community that has a history of isolation, taboo and shame to overcome. But resilience can only carry a movement so far.

For the rest. this movement, the European and Central Asian Intersex Movement, needs the means and the capacity to proceed while staying strong. It needs encouragement, protection and, last but not least, sustainable funding – during the crisis and beyond.

