



# Article Exploring the Experiences of People with Disabilities during the First Year of COVID-19 Restrictions in the Province of Quebec, Canada

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Abstract: During the COVID-19 pandemic, the province of Quebec, Canada implemented stringent measures to mitigate virus transmission, which considerably affected the life of people with disabilities (PWD). The objective of this study was to explore the experiences of PWD during the first year of COVID-19 restrictions across the province. Participants who self-identified as having a disability in the Ma Vie et la pandémie study (MAVIPAN) were invited to participate in a semi-structured interview between December 2020 and May 2021. A mixed inductive and deductive approach was used to conduct a thematic analysis using NVivo 12. Forty PWD from Quebec, Canada participated in the interviews (mean [SD] age, 55.4 [15.5] years, 50% women). A deterioration in mental health and a reduction in social contact with loved ones were reported. PWD experienced delays and cessation of health services and reported feeling at risk of contracting severe strains of COVID-19 because of their health condition. Enhanced difficulties experienced by PWD and the lack of consideration specific to PWD by public authorities during COVID-19 was particularly concerning for participants in this study. Future studies should explore the value of implementing social programs specifically targeting PWD to enhance support as the pandemic continues.

Keywords: COVID-19; people with disabilities; rehabilitation; qualitative

# 1. Introduction

In 2017, 6.2 million (22%) Canadians reported having one or more disabilities [1]. People with disabilities (PWD) often experience ableism, which is defined as stereotyping, prejudice, discrimination, and social oppression toward this specific population [2]. In Canada, 21.8% of PWD reporting poor health status also experienced discrimination or unfair treatment based on disability [3]. Furthermore, PWD commonly receive lower salaries and experience higher levels of violence and discrimination compared with people without disabilities [4,5].

During the COVID-19 pandemic, the government of Quebec, Canada implemented stringent measures to mitigate virus transmission, including limitations of personal contacts, closure of certain services, and a daily curfew [6], affecting the general population. For example, studies reported increase psychological distress [7], decrease in physical activities [8] and sleep disturbances [9]. These public health measures also considerably affected PWD, including difficulties in meeting financial obligations and basic needs [10] and job



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**Copyright:** © 2023 by the authors. Licensee MDPI, Basel, Switzerland. This article is an open access article distributed under the terms and conditions of the Creative Commons Attribution (CC BY) license (https:// creativecommons.org/licenses/by/ 4.0/). loss [11,12]. Moreover, PWD experienced limited transportation possibilities, restricted access to current communications and public health recommendations, and difficulties receiving required personal assistance, which made them more vulnerable during the pandemic [13,14]. A rapid review among people with physical disabilities highlighted the important challenges faced by PWD, such as limited access to healthcare services and home-based services [15]. Among individuals with intellectual and developmental disabilities, there was a greater risk of severe COVID-19 outcomes for those living in congregate settings [16]. In addition, this population reported increased mental health problems (e.g., anxiety), and discontinuation of disability-related services [17]. PWD faced additional challenges during COVID-19 that affected their rights as defined by the United Nations Human Rights [18].

Various studies have documented how people with disabilities experienced the pandemic around the world. However, few studies have been conducted in the province of Quebec in Canada. Given that Quebec experienced the highest incidence of cases and death associated with the COVID-19 virus during the early pandemic in Canada [19], it is important to examine the experiences of PWD in Quebec. Indeed, due to the different epidemiological situation in Quebec, in addition to governmental and cultural differences, it is possible that the experiences of PWD in Quebec may differ from Canadian provinces. To date, studies conducted in Quebec have included certain disabilities (e.g., spinal cord injury, traumatic brain injury) and have explored specific aspects of the impact of the pandemic (e.g., social support, and teleworking) [14,20–22]. However, no study to date has explored the global experience of people with disabilities at both the microsocial and macrosocial levels. It is relevant to conduct an in-depth exploration of pandemic experiences of PWD to inform decision- and policy-makers to better prepare for the long term impacts. Thus, the objective of this study was to explore the experiences of PWD during the first year of COVID-19 restrictions in the province of Quebec, Canada.

#### 2. Materials and Methods

# 2.1. Design and Participants

Participants were selected from the study "Ma vie et la pandémie au Québec/My life and the pandemic" (MAVIPAN) that aims to document and understand the consequences of the COVID-19 pandemic on individuals, families, communities and health and social services networks [23]. Complete details of the MAVIPAN study protocol, including description of the collected quantitative data, are published elsewhere [23]. Briefly, the recruitment began in April 2020 and ended in July 2021. Participants were recruited through the MAVIPAN website (www.mavipan.ca), mainstream media, social media, and mass diffusion across health facilities and universities. Participants were aged 14 and over, understood French or English, and lived in the province of Quebec, Canada [23]. On 1 April 2022, 3171 participants were recruited in the MAVIPAN study.

Participants were volunteers from a convenience sample of an ongoing study. For the present cross-sectional qualitative study, participants were purposively selected by their response "having significant and persistent impairments or disabilities that may present barriers to performing their daily life" in the MAVIPAN online questionnaire. Participants also gave their consent online to be contacted for subsequent studies. There were no exclusion criteria. A total of 334 people with self-identified disabilities registered in the MAVIPAN study, and 323 had agreed to be contacted again to take part into interviews. Between 16 December 2020 and 19 April 2021, an invitation was sent by email to 303 PWD. Of note, 20 participants did not receive the email invitation to participate in the interviews as they completed the online MAVIPAN questionnaire after the interviews were held. Those interested in participating in interviews contacted the research associate (J.L.) by email or telephone. This study was approved by the Ethics Committee of the Primary Care and Population Health Research Sector of the Quebec Integrated University Health & Social Services Center (CIUSSS de la Capitale-Nationale) (Reference number: 2021-2043), Committee of record, and the Ethics Committees of participating institutions. The

Consolidated criteria for reporting qualitative research (COREQ) checklist was used to guide this research [24].

## 2.2. Data Collection

Sociodemographic data were extracted from the MAVIPAN database [23]. Semistructured interviews (ranging from 9 to 88 min) were conducted by telephone or videoconference using platforms such as Microsoft Teams. No non-participants were present during the interviews, unless the presence of a caregiver or sign language interpreter was required by the participant. Interviews were conducted by two research assistants (N.-J.L. and N.F.-B.). Interviews were conducted between 16 December 2020, and 17 May 2021, corresponding approximately to the first year of the restrictions in Quebec, Canada.

Participants did not have access to interview questions prior to the meeting. A specific interview guide, developed by a multidisciplinary team of researchers, with questions tailored to PWD was used to explore subject relevant to PWD experiences such as difficulties, good times, strategies developed, access to services and experience of social distancing (see Supplementary Materials for interview questions). All interviews were audio or video recorded.

An informed consent form was emailed to the participants prior to the interviews. A verbal consent script was read to participants by the research assistant prior to the interview. All interviews were transcribed by research assistants (N.-J.L. and N.F.-B.). Transcripts were not returned to the participants for validation.

## 2.3. Data Analysis

Line-by-line coding and thematic analysis were carried out by two research assistants (N.-J.L. and N.F.-B.) and a research associate (D.B.) [25]. The analysis was conducted in the original language to limit interpretation of translations. After familiarization with the data, coders (N.-J.L., N.F.-B. and D.B.) independently coded one interview to ensure common understanding of the codes. The remaining interviews were divided among the two research assistants and coded separately (N.-J.L. and N.F.-B.). A research associate (D.B.) supervised the coding to verify the research process and increase credibility [26]. The two data coders (N.-J.L. and N.F.-B.) met weekly (at minimum) to interpret data and to generate themes. In addition, the two data coders (N.-J.L. and N.F.-B) and the research associate (D.B.) met weekly to follow up on the analysis of the interviews.

A mixed inductive and deductive coding approach was used to determine themes. Some codes were defined prior to analysis according to the topic surveyed in the interview guide [27]. Once analysis began, additional codes were added, modified, or deleted depending on the data during the weekly discussions between the coders. When all the interviews were coded, the three coders met to ensure that the codes represented the data (combining code, discarding, and creating new codes) and to name and define each theme. Data saturation was met as no new themes or subthemes emerged from the data and the team reached consensus on themes and subthemes during analysis [28]. Qualitative analysis software NVivo 12 (QSR International, Melbourne, VIC, Australia) was used [29]. Moving from a microsocial to a macrosocial perspective, we identified and categorized the major themes based on the areas of life impacts of the pandemic.

# 3. Results

A total of 44 participants responded to the email invitation, and 40 were interviewed. Reasons for refusing to take part in the interviews ranged from people no longer feeling concerned by the project, lack of time, or simply not replying to the invitation e-mail. The mean age (SD) of the participants was 55.4 (15.5) years and twenty (50%) identified as women. Participants reported predominantly mobility, flexibility, pain, and visual disabilities (all sociodemographic information is presented in Table 1).

Characteristics	n (%)
Age, years (mean [SD])	55.4 [15.5]
Sex	
Women	20 (50.0)
Men	19 (47.5)
Gender-fluid, non-binary and/or two-spirit	1 (2.5)
Disability categories <sup>1</sup>	
Seeing	11 (11.5)
Hearing	6 (6.3)
Mobility	19 (19.8)
Flexibility	14 (14.6)
Dexterity	8 (8.3)
Pain	17 (17.7)
Learning	1 (1.0)
Developmental	1 (1.0)
Intellectual	1 (1.0)
Mental health	8 (8.3)
Memory and/or cognitive	7 (7.3)
Language	2 (2.1)
Other	1 (1.0)
Dwelling	
Community dwelling (e.g., home and	36 (90.0)
apartment)	30 (70.0)
Long-term care home	2 (5.0)
Residence for autonomous seniors	1 (2.5)
Others	1 (2.5)
Highest diploma, trade certificate or degree	
completed	
Less than a high school diploma or its	1 (2 5)
equivalent	1 (2.5)
High school	7 (17.5)
College	14 (35.0)
Undergraduate university degree	14 (35.0)
Graduate university degree	4 (10.0)

 Table 1. Characteristics of 40 people with disabilities from Quebec province (Canada) during the COVID-19 pandemic.

<sup>1</sup> Participants could select multiple categories. Disability categories were derived according to Statistics Canada [30].

Seven main themes presenting the impacts of the pandemic on PWD were identified, including: (1) Mental Wellbeing and Physical Health; (2) Leisure and Professional Activities; (3) Social Relationships; (4) Services; (5) Perceived Treatment of PWD During the Pandemic; (6) Perception of Health Measures and of the Risk Posed by the COVID-19 Virus, and (7) Perception of the Future.

# 3.1. Mental Wellbeing and Physical Health

Participants experienced variable pandemic-related impacts on mental wellbeing and physical health. Some participants reported a deterioration of their mental health and the presence of depressive symptoms such as anxiety, fatigue, anger and isolation:

I had exams that were supposed to take place that were cancelled, that created a lot of stress and ... Oh yes I'm anxious too, I have anxiety. A little complement. So, it really created a state of insecurity and increased stress, and therefore pain and fatigue, which was also linked to that.

(A man of 71 years old having a mobility disability)

Conversely, other participants expressed feeling less alone because the whole population was living a similar experience:

*I feel less alone. I feel more like we are all in the same boat.* 

(A woman of 29 years old having a pain disability)

and/or cognitive disabilities)

Some participants reported that they felt as if they were already living in confinement due to their disability:

*The reality of someone living with a disability is that they are confined for their entire life.* (A man of 55 years old having mobility, flexibility, dexterity, pain, and memory

Besides, some felt that past experiences in dealing with their disability provided them with the strength to get through this pandemic period:

Before the pandemic, if before the pandemic I hadn't had the medication and all the background [experience] that I had, I would have gotten through it, but much harder.

(A woman of 49 years old having a mental health disability)

In this regard, some participants said that they did not experience any difficulties related to their mental and physical health, since their situation was a continuation of their pre-pandemic daily life:

I think that our community suffers less because of the isolation because there are other things that I told you about that we suffer, but personally, I don't live it because it's my everyday reality, so it hasn't changed anything.

(A man of 55 years old having mobility, flexibility, dexterity, pain, and memory and/or cognitive disabilities)

In fact, a few participants highlighted that this pandemic period was an opportunity to appreciate life to a greater extent. Of note, the impacts of health measures on autonomy were mixed; with some participants reporting reduced autonomy and others not feeling affected.

Participants also reported changes in physical health due to the cessation of rehabilitation services and fewer opportunities to participate in physical activity which was attributed to a loss of physical abilities:

There's my physiotherapy too that I was cut off for two months last year. When I stopped my physiotherapy last year, for two months before it started again, I had lost a lot of functions, at the functional level, I was limping, I had a cane. Two months, no physiotherapy, it was huge. I found that hard too.

(A woman of 52 years old having pain and mental health disabilities)

Few participants also described how the integration of sanitary measures into daily life, such as waiting lines to enter the grocery store and working from home with uncomfortable equipment (e.g., chair and desk), caused them additional physical pain or discomfort:

If I wanted to go to the market, like go to the grocery store, when I got to the market and there was a line of people waiting, I had to go home, because my leg goes numb when I'm standing still. So, sometimes I would go to the grocery store four times before I was able to get back to the store without a line.

(A woman of 77 years old having mobility, flexibility, and pain disabilities)

In sum, regarding the impacts of the pandemic on well-being and physical health, some participants highlighted a deterioration of their mental and physical health, and others did not experience any difficulties related to this theme.

# 3.2. Leisure and Professional Activities

Some participants discovered new leisure activities and interests, such as walking in the woods, reading more books, and doing exterior maintenance on their homes. Partici-

pants also developed new ways to exercise. For example, due to the closure of the training rooms and group sports activities, some participants took part in online physical activities, while others increased participation in outdoor activities. In this regard, a participant described how physical activities were essential for them and provided a distraction from thinking about COVID-19.

However, other participants reported experiencing several constraints to carrying out their leisure activities and that they consequently limited themselves to participation in essential activities:

That's one of the reasons why I don't go out a lot, well I don't go out a lot, I don't go to the grocery store or anything, it's so I don't have to put on a mask, I just go out when I have to go out, [i.e.,] when I have my medical appointments and my treatments and my psychologist. Other than that, I don't go out. I go out once a week and that's it.

(A woman of 52 years old having pain and mental health disabilities)

In fact, some participants highlighted a reduction or cessation of cultural activities, such as visits to theatres and cinemas, which facilitated learning new things. A participant with a deaf partner reported that leisure activities provided an opportunity to socialize with others. Thus, the constraints associated with health measures added to the barriers already experienced due to the participant's disability:

At the same time, it just had a big impact on my activities because already there was a big impact on my stroke and in fact, I didn't have that mobility anymore, they took away my license. So, on top of that, even, even the things that I could do without a license, well I can't do them anymore. So, it was like, when it was like adding a layer to what was already there [ ... ]. They always say it couldn't be worse, but here I think it could have been worse, but I don't dare say it couldn't be worse because I'm afraid.

(A man of 52 years old mobility and mental health disabilities)

Despite the adaptative measures they had to take, some participants mentioned that participating in their leisure activities remained as fulfilling and satisfying as before the pandemic.

Participants also reported impacts on their professional activities. First, volunteer activities that were meaningful to the participants were interrupted:

I used to volunteer, I can't do it anymore because of my health difficulties, they preferred not to take me during the pandemic so as not to put me at risk [...], they didn't want to expose me to COVID.

(A woman of 52 years old having pain and mental health disabilities)

Moreover, these activities represented opportunities to socialize with other people and to learn new things. Second, participants felt that the pandemic changed their access to education. For example, one participant expressed that the pandemic created an opportunity to return to school, but another stated that distance learning was difficult. For the few participants who reported being employed during the pandemic, transitions to remote work and instability concerning the work schedule were a common occurrence:

Well, at the beginning, in March, I was not on leave, they put us on leave, then after that, they rehired us 25 hours a week, after that it was 35 hours, they rehired us full time.

(A woman of 63 years old having mobility, flexibility, and pain disabilities)

Among the participants who experienced remote working, the use of digital technologies was predominant. Similarly, a participant having vision and hearing disabilities reported that using email for work was an additional communication challenge, and that they required assistance from another person to accomplish vocational tasks.

In sum, some participants changed or maintained their leisure and work-related activities by reducing, stopping, or continuing their normal activities. While the pandemic had little effect on some people's activities during this time, it provided an opportunity to learn new things for others.

#### 3.3. Social Relationships

Participants reported a decrease in opportunities for social activity such as shared meals with friends and family, resulting in less contact (especially physical contact) with their loved ones:

I didn't see anyone. Luckily, I had Zoom with friends on Friday nights, but other than that, I didn't see anyone. I live alone and I have a friend that comes over on the weekends, but I mean, it's very hard to ... I find that I've lost vocabulary and not talking and not talking, I was at a point where, I've been to the hospital 18 times for my leg, I was at a point where I couldn't wait to go to the hospital to meet someone and talk. It's not fun when you're at the point where you're happy to go to the hospital.

(A woman of 77 years old having mobility, flexibility, and pain disabilities)

Some participants expressed the feeling of losing significant quality time with important people. Conversely, other participants reported a minor impact on their social relationships as they commonly experienced solitude before the pandemic. In this regard, a few participants reported that PWD were already more isolated in winter especially due to the challenging transportation conditions caused by the weather. Some reported how using digital technology facilitated the maintenance of contact with loved ones. However, the use of technology had certain drawbacks, such as the lack of physical contact, which limited satisfaction provided by with digital tools:

It's hard to live with [social distancing] I am a person who, first, needs others and others need me. So, at the beginning it was fun, we met on Zoom, on Teams, on Messenger, some kind of virtual happy hour, it's always fun at the beginning and it's funny, we put little pictures and sometimes we dress up and it's really funny, but at some point, people get off that.

(A woman of 53 years old having a mobility disability)

Other participants continued to see their families, while incorporating sanitary measures to reduce the risk of contamination (e.g., masking and social distancing, seeing each other outside).

In sum, regarding the impacts of the pandemic on social relationships, participants experiences were mixed. Some reported a reduction in social contact with loved ones and others reported little change compared to their pre-pandemic experience.

#### 3.4. Services

Some participants reported experiencing delays in services, while others reported complete cessation of services during the pandemic. Specifically, medical, psychological appointments, and home care services were disrupted:

Well, it's in terms of everything that happens with our home help, that's hell. There are no more services. I need help to do my housework, that's for sure, but I need help for other things than that. Like taking a shower, etc. It's hours that are allocated to me because I'm entitled to that. But there is no one who offers services anymore, because everyone, there is no one who wants to go out of their house to give services to someone who is "sick".

(A man of 55 years old having mobility, flexibility, dexterity, pain and memory and/or cognitive disabilities)

In addition, some reported having difficulty obtaining quality services, mainly due to a lack of coordination between the different services and staff turnover:

[...] It's just that there are fewer staff on the floor, sometimes instead of four there will just be two. So, they're going to move my hours of service: "Oh, tomorrow you have to get up earlier". I'm kind of forced to, I can't really say no. But it's certain that because the staff ... Since there's no more rotation, well then, they're going to make cuts, and when we see that they're in a hurry, we're going to ask for less, we're going to do without, or they're going to say to us: "Can you come back later", or they forget about us. It's

normal, because instead of being four, they are two. It's all small changes daily. It comes a burden in the end.

(A woman of 45 years old having a mobility disability)

In this regard, a participant felt abandoned by the health and social care system. Another participant stated that salary support for caregivers was non-existent or very low even during the pandemic. A few participants experienced stress due to the fear of not being able to obtain services or medication. Of note, two participants reported a lack of adapted resources for PWD:

#### Many businesses and services have stopped offering accommodations for people like me.

(A woman of 40 years old having a vision, mobility, dexterity pain and memory and/or cognitive disabilities)

Some participants reported that their cherished ones were helping them, some even before the pandemic, which helped offset the lack of services. In this regard, one participant mentioned that the services obtained before the pandemic already had to be assumed by a partner without remuneration even if that partner had to work at the same time.

Some participants used digital tools to have their medical appointments. However, opinions were mixed about the use of telephones for conducting medical appointments, particularly due to feeling an impersonal contact with the professional. Of note, some in-person medical appointments had resumed at the time of the interviews, which was reassuring for participants. Furthermore, some people reported that they had not encountered any difficulties in the provision of services:

Well, I certainly had a direct telephone number with my psychiatrist at the hospital, so I didn't see any change: she returned my calls, no problem. Even my family doctor, like the prescription, she was quite accessible within 48 h–24 h I had access to her to chat a little bit and things like that.

(A woman of 49 years old having a mental health disability)

In this regard, a participant reported a better communication between doctors and pharmacists since the prescriptions were sent directly to the pharmacy, which was a positive change.

In sum, regarding the impacts of the pandemic on services, PWD reported that the accessibility of services was modified by integrating a virtual service offering, while others experienced delays and even interruptions in services.

# 3.5. Perceived Treatment of PWD during the Pandemic

The perception of the treatment of PWD during the pandemic by the population and governments was mixed among the participants. Most participants indicated that public authorities lacked consideration for PWD and that it took the public authorities a long time to create specific recommendations for PWD in the pandemic:

# *They don't care about us. I don't think there's any help for us, I mean, I don't even know where to call if I need help.... I find it terrible; I find that a lacks consideration ... We are forgotten and that is sad.*

(A woman of 66 years old having mobility, flexibility, dexterity, and pain disabilities)

For example, participants stated that PWD were not given priority in the vaccination schedule, while others reported various shortcomings in home care. Indeed, as the pandemic continued, a few PWD would have liked to have had a faster access to vaccines. Especially since they felt vulnerable because of their health condition, regardless of their age. In addition, participants mentioned trivializing gestures, and speech towards them from the general population and the government:

Sick people in general, we all took a back seat because we weren't too important, we weren't the ones who made the economy go round, on the contrary, we were expensive.

And then there was a kind of ambient discourse in the population "but they're going to die anyway" or ... there was a lot of this discourse where old people "well, they're old anyway", sick people "well they're going to die anyway".

(A woman of 29 years old having a pain disability)

Among the various suggestions, participants indicated that public authorities should offer a better service of accompaniment to PWD to better clarify information, to support them in their outings, to facilitate their appointments, to have access to interpreters and to help them at home, among others. One participant suggested that the government should have offered alternatives to people who were already cut off from their resources. However, a few participants believed authorities had responded adequately, expressing that PWD were not a priority group in the early pandemic in their opinion:

*Of course, we are not the most valued clientele. But it can be understood. It can be understood, and I understand in the context, especially in the context of the first wave, well, so it was new, so I can understand.* 

(A man of 23 years old having a mobility disability)

In sum, participants highlighted a lack of consideration for the specificities of PWD and even trivializing gestures and speech toward this population.

#### 3.6. Perception of Health Measures and of the Risk Posed by the COVID-19 Virus

Opinions were divided on the perception of the various protective measures put in place by the government such as social distancing, masking, and curfew, for example. Several participants stated that they disagree with certain measures put in place by the public authorities. While some would have preferred protective measures to be implemented faster and more severely, others criticized some measures that caused the cessation of certain services, such as the prohibition of family caregivers in establishments and the cessation of activities. Nevertheless, most of the participants reacted well to the arrival of measures such as social distancing, wearing face masks, and curfews, suggesting that these were habits proacted by some PWD before the pandemic:

It was already in my daily life, I already wore a mask to go to the hospital or to family parties where there were more than ten people or if there were children, things like that to protect me. So, that was already something I knew well.

(A woman of 40 years old having a vision, mobility, dexterity pain and memory and/or cognitive disabilities)

However, a few participants indicated that they felt a sense of inconsistency due to travel discounts offers by airlines or the opening of stores when other infrastructures were closed. Most participants condemned the non-compliance to the protective measures by other people. Indeed, participants reported that people not complying with the protective measures lacked awareness regarding the potential risks and criticized the fact that those people continued to travel.

Participants were aware of the risks posed by COVID-19. In fact, participants reported feeling more at risk of contracting severe symptoms due to their disabilities, which led to several concerns:

In a disabled person or in a person who has more fragile health, basically, who has nothing to do with COVID-19, it's insecure, because people, well, we won't go to the hospital because, we think that we could perhaps have more one [ ... ] We are always cautious, and we are always on our guard.

(A man of 48 years old having mobility, dexterity and pain disabilities)

To avoid catching the virus, people integrated barrier gestures in their daily life, such as maintaining a physical distance when they received home help and not going to places where protective measures could not be respected. Finally, participants incorporated several strategies to mitigate the risk of infecting their loved ones:

My family, the people are all quite old [...] They are all at risk, and as I go to physiotherapy, they are all a bit afraid of me. It's normal too, it has consequences, so they put me in quarantine because I often go to the hospital, but they are right. It's a pity because I went back to my family after four years to reconnect with everyone.

(A woman of 49 years old having mobility, flexibility, dexterity, and pain disabilities)

Moreover, some participants indicated that they would have preferred more stringent protective measures or that protective measures should have lasted longer to definitively eliminate the risks of catching COVID-19.

In conclusion, participants opinions were mixed when it came to the protection measures and their application. Some pointed out inconsistencies and consequences of these measures, while others would have preferred more severe measures. All in all, most of the participants have integrated the protective measures into their daily lives.

#### 3.7. Perception of the Future

As for post-pandemic perceptions, opinions were mixed among participants. Related to the vaccine, some PWD hoped for a return to normal daily life. Many associated a positive perception of the future with being able to see those around them again or being able to resume their daily activities:

It's going to be the sun, the sun after the storm. It's going to be great; we're all going to be happy to see each other again.

(A man of 71 years old having a hearing disability)

Nevertheless, the pandemic caused many changes, requiring a period of adaptation. Indeed, one participant indicated that although the pandemic induced positive changes, there will remain a certain nostalgic feeling that certain things have been lost or will not be experienced again.

Some participants mentioned concerns about what the future could entail for their health. Indeed, one participant was afraid that life would return to normal for a large portion of the population, while PWD would still be struggling with health problems:

So, I'm afraid that my health won't get any better when it's over, that my problems won't be solved and that everybody's life will go back to normal ... that everybody's life will go back to normal and I'll still be behind, dealing with my autoimmune disease, my chronic migraines, all my other problems.

(A woman of 29 years old having a pain disability)

One participant indicated that the pandemic furthered their isolation and pain due to the progression of their disability during the pandemic, and they had initiated the steps to register for medical assistance in dying:

My disability is progressing [...] And, as I am at home, all day [...] Feeling how my body is so unpleasant. How it becomes more and more painful. Me, it is certain and certain that I have already started medical aid in dying procedures, so, is this the confinement? No, it's not the period, but it surely adds to the isolation and the thoughts that come with being all alone and not feeling well like that, I'm more tempted to fight with a body which hurts me there.

(A man of 55 years old having mobility, flexibility, dexterity, pain and memory and/or cognitive disabilities)

Furthermore, a participant who is a parent of three children who has been limited in contact and activities during the pandemic expressed concern about the uncertainty of what the future will be like for children. Similarly, other participants did not see much hope for a brighter future due to the various global crises. Finally, some participants were uncertain regarding the evolution of the pandemic. Indeed, some questions remained about the vaccine, e.g., whether the vaccine would be effective in the long term or only for a short period. In conclusion, participants were eager to get back to their usual activities, while others had concerns about the long-term consequences of the pandemic.

#### 4. Discussion

Even before the pandemic, PWD were more likely to have poorer mental health than people without disabilities [31,32]. In fact, a previous study conducted before the pandemic reported that Canadians with learning disabilities were more likely to report high levels of distress, depression, anxiety disorders and suicidal thoughts than Canadians without disabilities [33]. In the present study, a deterioration of the mental health of some PWD in comparison with before the pandemic was reported. This finding is similar to a study conducted during the pandemic among adults with autism, which reported increased mental health problems such as depression and anxiety symptoms [34]. As such, affordable and accessible professional support for managing mental health among PWD during the pandemic and beyond is important [34].

Most participants described reduced frequency of their social contacts with family and friends, which is consistent with government recommendations during the pandemic [6]. Although this result was not specific to PWD (i.e., the protective measures were targeted for the whole population), social relationships are particularly important for PWD, as these relationships often play an important role in their mental health and wellbeing [35]. However, while reduced contact was difficult during the pandemic for adults with autism, a study reported that they felt relieved from social stress [34]. Lake et al. also illustrated that adults with intellectual and developmental disabilities demonstrated resilience in the context of rapid changes and adaptation needed due to the pandemic [36]. All in all, there is likely an interplay between the specificity of the disabilities experienced and the need for social contacts, among others.

In the present study, assistance from family and friends for making essential purchases (e.g., groceries), was highlighted as a facilitator to overcome the pandemic-related difficulties. A study conducted among adults with intellectual and developmental disabilities highlighted that more frequent support or contact from family members would have helped to feel better during the lockdown [37]. Other studies have suggested that the voluntary assistance from relatives and friends compensated for lack of certain services, such as home help [37,38]. However, it was not unanimous among participants in this study. Considering the important help offered during the pandemic, future studies should consider the experiences of persons with disabilities who did not receive this kind of social support.

In the province of Quebec some protective measures implemented at the beginning of the pandemic may have influenced the ability of relatives to provide support. For example, physical distancing measures, prohibition of all indoor and outdoor gatherings, mandatory confinement in seniors' residences, curfew and forbidding travel between certain regions [6]. In this regard, findings from a survey of informal caregivers in Quebec highlighted reduced physical and mental health, absence of financial assistance and lack of resources to support the person they care for as the major impacts of the pandemic [39]. While some policies are in place in Quebec to support caregivers (e.g., tax credits) [40], several eligibility requirements must be met limiting how caregivers may have accessed this assistance early in the pandemic. It is therefore crucial to prepare for long term impacts of the pandemic and future crisis. For example, the Quebec government should rapidly development and implement clear and detailed instructions for informal caregivers to facilitate the essential support they provide to their loved ones with disabilities. Due to the important social support role provided by relatives and friends during the pandemic, future studies should also examine the experiences of unpaid caregivers during the pandemic.

This study highlighted that PWD experienced delays and disruptions in services during the pandemic, which has been supported by the literature [14,15,38,41]. However, these delays and disruptions in obtaining services have been particularly difficult for PWD since they already experienced challenges in obtaining high quality health care before the pandemic [42]. For example, specific transportation challenges regarding accessibility

of services were reported in the study of Vries McClintock et al. [42]. According to a study conducted in Quebec, Canada, the pandemic has exacerbated the already strained availability, distribution, training, safety and protection of health care personnel, which may partly explain the changes in the provision of services to PWD [43]. In the present study, some PWD reported using technology for medical appointments [44]. However, as illustrated in our study, the use of technology to receive health services presented several challenges and the appreciation was variable. A previous study conducted in Canada among adults with intellectual and developmental disabilities reported lack of access to the necessary technology and lack of skill or discomfort as the major barriers to accessing technology for virtual care for PWD [45]. Thus, care must be taken to ensure that technology use does not pose an additional restriction that may exclude an already vulnerable population, such as PWD. In addition, it is critical to consider the preferences, needs, capabilities and environmental resources of PWD for technology use [45].

Due to the PWD health conditions, some participants felt more at risk of contracting a severe form of the disease. In this regard, few participants would have preferred to be considered a priority population for the COVID-19 vaccine. In Quebec, governments primarily prioritized vaccination schedules according to age. PWD were prioritized as 8th among 11 ranks, just ahead of the general population [46]. Given that COVID-19 was suggested to pose a greater risk to PWD, especially for younger people [47], PWD were not adequately prioritized for vaccination according to a few participants of the present study. Study suggested that a lower propensity to risk-taking behaviours coupled with the fear of negative health outcomes is associated with a better compliance with sanitary measure, and in turn, a decreased risk of catching COVID-19 [48]. However, difficulties in accessing health information for PWD, particularly in the early stages of the pandemic, have been reported [49]. Trust in information [50] and accessibility [51] of the information for PWD were associated with better compliance with recommended sanitary practices. These findings highlighted the importance to provide information tailored to PWD such as sign language interpreter and web accessibility guidelines, which may have been lacking during the pandemic [49,52].

Finally, our findings highlighted that participant felt under considered during the pandemic, as there was a lack of specific guidelines and considerations for PWD. In fact, the trivializing discourse towards PWD that some participants in our study reported from parts of the general population and government could be seen as a consequence of ableism [2]. This result is consistent with a review of the health measure specific to PDWs conducted in multiple countries by Lugo-Agudelo et al. which revealed that only half of the countries examined implemented measures specific to PWD as well as a lack of support to provide rehabilitative care to PWD during the pandemic [53]. PWD have been experiencing social exclusion and lack of consideration of their specificity by the government long before the pandemic. Indeed, during the first months of the pandemic, home care services and family support and rehabilitation services were suspended, except for those deemed essential [19]. The nature of the public health measures implemented in Quebec also had direct impacts on the experiences of PWD in terms of social distancing, travel constraints, new interior design, and wearing masks [19]. For example, the number of people permitted to enter some businesses was restricted in Quebec [19]. In some cases, PWD were required to enter stores alone (i.e., without their caregiver) despite the need for support and had to wait in line outside to respect the capacity limits [54]. Thus, the continuity, and even the increase of the invisibility of governmental authorities towards PWD and the exclusion experienced by this population during the pandemic has highlighted the difficulty of protecting the rights and dignity of PWD [54,55]. However, a study suggested that the pandemic context may be an opportunity for a more inclusive society. Indeed, sharing a common experience with PWD can offer an understanding of the pre-pandemic living conditions of this population [56]. It is also crucial that new regulations, policies or laws respect the rights of PWD, ensuring no additional restrictions that could worsen a sense of invisibility in society [54]. In this regard, the United Nations has suggested that PWD be consulted and involved in the response

to the pandemic to ensure inclusive practices and policies that are consistent with their needs [57]. In fact, some countries have developed specific protection measures for PWD at the beginning of the pandemic, such as communicating official information through special channels or lines designed for people with hearing disabilities, and offering content through the Braille Writing System for people with visual impairments [53].

The study limitations must be considered when interpreting the results. First, participants were volunteers from a convenience sample on an ongoing longitudinal study and the data collected is only representative of people living in the province of Quebec. PWD in other provinces were not consulted. However, the qualitative design allowed for an in-depth understanding of the participant's viewpoint [58]. Although we did not code for inter-coder reliability during the analysis, frequent meetings ensured consensus through discussion. In addition, the deductive analysis was not based on a theoretical framework, but rather on the main topics covered by the interview guide that was developed by a multidisciplinary team of researchers. Our study included PWD with several types of disability, and we could not distinguish between disabilities considering our small sample size. This issue reduced our ability to accurately compare our findings with those from other studies based on people with specific disabilities.

#### 5. Conclusions

In summary, mental and physical health impacts, reduced social contact with loved ones, and temporary disruption and delay of services were reported during the first year of the pandemic. In addition to these difficulties, participants reported inadequate specific considerations specific to PWD during the pandemic. For those individuals who identified themselves as having significant and persistent impairments or disabilities likely to encounter obstacles in carrying out their daily activities, the relation between additional difficulties and lack of consideration by public authorities was particularly concerning. Future studies should explore the value of implementing social programs specifically targeting PWD to provide better support as the pandemic continues. In this context, it will be relevant to observe the long-term effects on PWD health status and accessibility to quality services, among others.

**Supplementary Materials:** The following supporting information can be downloaded at: https: //www.mdpi.com/article/10.3390/disabilities3010002/s1, File S1: Individual interview questions for people with disabilities.

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**Data Availability Statement:** The MAVIPAN Database will be shared in accordance with the Canadian Institute of Health Research (CIHR) joint statement on sharing research data, the FAIR Guiding Principles for Scientific Data Management and Stewardship, and the norms established by the Ethic Committee of record. Data are available from the MAVIPAN study coordinator (contact via mavipan.ciussscn@ssss.gouv.qc.ca) for researchers who meet the criteria for access to confidential data.

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