

# How Did People with Impairments Perceive Public Information During the COVID-19 Pandemic and What Are Their Suggestions for Accessible Crisis Information?



## RESEARCH

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## ABSTRACT

The aim of this study was to explore how people with impairments perceived the accessibility of information regarding the COVID-19 pandemic in Sweden and what improvements they suggest to ensure accessibility of information in future societal crises.

The study had a descriptive design, involving interviews and focus group discussions with people with impairments and their representative organisations, alongside analysis of public crisis information websites.

The results showed that while many people with impairments could use their usual information channels, other found that the adapted information they needed was missing and that the government agencies, regional healthcare organisations and local municipalities were unprepared to produce accessible information.

In conclusion, society exhibited shortcomings in providing accessible information to people with impairments during the COVID-19 pandemic. The responsible authorities seemed unprepared to provide accessible information. Proactive planning and training are imperative to ensure the provision of accessible information in future crises.

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One of the most important roles that the authorities have is that of protecting all citizens from harm and helping people prepare for and manage emergencies and crises, especially people with impairments (Alexander 2012; Prasad 2022). A vital part of crisis management is to ensure that all citizens can access information and that communication is adapted to the needs of people with such impairments that affect their ability to retrieve and process information, and to communicate (Annaswamy, Verduzco-Gutierrez and Frieden 2020; Baxter et al. 2021; Jumreornvong et al. 2020; Meltzer 2020). Accessible information can reduce vulnerability among people with disabilities but also in culturally and linguistically diverse communities (Vázquez and Torres-del-Rey 2019). Hence, crisis information and communication should also be accessible and understandable for people with impairments during the whole length of a crisis cycle, before, during and after (Jumreornvong et al. 2020; Prasad 2022). Early in the COVID-19 pandemic, accessible information was identified as a key to prevent the discrimination of people with disabilities when societies responded to the pandemic (Armitage and Nellums 2020; United Nations 2020). To be accessible and usable, Meltzer argued that information needs to be accurate and of high quality, timely, kept up-to-date, provided in sufficient detail and breadth, and produced and disseminated in collaboration with people with impairments (Meltzer 2020).

Prasad argues that crisis communication should be prepared in advance and using templates to fit the specific crisis and to fit the information and communication needs of people with impairments. Preparation before a crisis would facilitate instant provision of accessible information during all phases of a crisis (Prasad 2022). As part of pre-pandemic preparation Baxter argues that digital platforms must be developed and tested in a co-design process to be accessible for elderly people (Baxter et al. 2021). Since a large proportion of information and communication uses internet as a channel it is especially important that online information and communication is perceived as accessible for all citizens, but previous studies show that people with impairments feel that they are not equally included in the digital society (Johansson, Gulliksen, and Gustavsson 2021).

There is a growing body of literature on how information providers succeeded in producing accessible information during the COVID-19 pandemic. Overall the literature show that crisis information and communication during the pandemic often failed to reach people with impairments (Annaswamy, Verduzco-Gutierrez and Frieden 2020; Prasad 2022). When healthcare providers turned to eHealth solutions to mitigate the risk of virus transmission many providers did not take into account accessibility needs of people with low vision, deaf people or people with cognitive impairments (Annaswamy, Verduzco-Gutierrez and Frieden 2020). Several studies that used automatic tools for evaluating crisis information on websites in relation to the Web Content Accessibility Guidelines, WCAG (W3C 2017) have reported significant deviations from the standard (Acosta-Vargas et al. 2022; Alismail and Chipidza 2021; Ara and Sik-Lanyi 2022; Dror et al. 2021). In one of the studies, evaluation with automated tools was complemented with an expert evaluation (Fernández-Díaz et al. 2020). A study investigating the accessibility of statistical charts (Alcaraz-Martínez & Ribera-Turró, 2020), used heuristic guidelines to find that government and healthcare providers often used charts for conveying, clarifying and simplifying crisis information but failed to present this information accessibly for people with low vision. Worrall et al. investigated the readability of online healthcare information in English speaking countries by using readability assessment tools. They found that readability in general was poor with public health websites and government websites performing somewhat better than media websites (Worrall et al. 2020). Three other studies that used a similar approach, also found the readability level too difficult for many readers (Mac et al. 2021; Valizadeh-Hagh, Khazzal, and Rahmatizadeh 2021; Wrigley Kelly et al. 2021). Some easy-to-read material scored better in readability tests but those information texts were few and often hard to find (Mac et al. 2021). A survey on health literacy, showed that deaf people reported more problems with accessing, understanding, and trusting COVID-19 information compared to people who were hearing but nevertheless had similar knowledge about how to mitigate virus transmission (Panko et al. 2021). A survey targeting blind people and people with low vision found that they often perceived the information about the pandemic incomprehensible (Fabac and Sikirić 2023). Younger people in this population struggled more than older, which was explained by the older used traditional radio and TV broadcasts to get their information while younger

blind persons or persons with low vision used modern technology and faced more accessibility problems. In summary, most of the literature on accessibility of crisis information during the pandemic consists of expert evaluations or conformance evaluations in relation to standards for accessibility. To the best of our knowledge, there are no studies using interviews and focus group discussions to in-depth explore the views and experiences of people with impairment.

In this paper, we use terminology in line with the social model of disability. This means that we distinguish between ‘impairment’, defined as ‘problems in body function or structure such as a significant deviation or loss’ (World Health Organization 2002), and ‘disability’, which is viewed as a social construction as described by the social model of disability (Oliver 1996) and as a form of oppression imposed by society (Abberley 1987). We are aware of that the use of the terminology ‘impairment’ versus ‘disability’ is debated. However, we believe, in line with the social model of disability, that it is preferable to refer specifically to ‘impairment’ when relating to functional limitations. In this paper, we use a terminology that clearly distinguish between impairment and the disabling processes in society ending with people being disabled. In our view, this distinction is at the core of the social model of disability. In an accessible society, an impairment would not automatically mean disability (Johansson 2019). Our position is that people with impairments often are disabled by inaccessible design of societal structures and systems. Hence, to prevent disablement it is important to focus on how people with impairments can have a voice in the design of all aspects of the society (Davis and Andrew 2017).

## THE SWEDISH CONTEXT

Difficulties with processing information and communicating can be observed across various diagnoses and impairments, manifesting as specific reading, understanding and communication difficulties (Bonifacci and Snowling 2008; Das et al. 1982). The Swedish Agency for Accessible Media (MTM) have identified types of impairment that might need specially adapted information to perceive the information as accessible, namely: people who are blind or who have low vision, people with reading and writing difficulties, people with mobility or hearing impairments, people with intellectual disability, and neurodiverse people for example with autism and ADHD, Attention Deficit Hyperactivity Disorders (The Swedish Agency for Accessible Media 2024).

A variety of adaptations and formats are needed for information and communication to be perceived as accessible by people with impairments (Eriksson and Nyström Höög 2023). Adaptations could be to provide easy-to-read text versions (Foley 2011; The Puzzle Project 2017), complement text with pictograms or pictures, or to provide information in sign language. Text also needs to offer the possibility to convert to speech or to braille. For some, spoken information presented in audio or video format is better than text. In a crisis such as the COVID-19 pandemic people with impairments are especially vulnerable. Ensuring that communication and distribution of information to the public, also reach specific populations at risk is crucial to be able to convey information on measures to be undertaken to mitigate the crisis (Battle 2015; Kent and Ellis 2015; Marciniak 2023; Mitchell and Karr 2014).

From the start and throughout the pandemic, the Swedish authorities’ strategy to manage the COVID-19 pandemic was primarily to provide citizens with information and recommendations on how to prevent infection and the spread of the virus, which were conveyed to the population through all types of media channels. The Swedish Public Health Agency issued recommendations on how to prevent COVID-19 infection and the spread of the virus, by three simple rules: keeping distance, washing hands and staying at home when having symptoms (Public Health Agency of Sweden 2020) There were very few mandatory rules or regulations issued, and the authorities did not implement any punitive measures (Andersson and Aylott 2020; Brusselaers et al. 2022; Grothe-Hammer and Roth 2021; Lindström 2021). Consequently, the effectiveness in distributing information and communication regarding the recommendations played a crucial role in shaping the outcome of the strategy and in protecting Swedish citizens.

The rationale for this study is that since Sweden is a welfare state having high ambitions to care for all citizens in its society, including people with impairment, it is important to investigate how groups in the population that have been described by the Swedish authority MTM as groups who

need specially adapted information, actually perceived the information during the COVID-19 pandemic, and if they perceived the information as accessible.

## AIM

The aim of this study was to explore the experiences of people with such impairments that according to the MTM definition, could affect the ability to perceive, retrieve and understand information, concerning the research questions:

- 1) How did people with impairments in Sweden perceive the accessibility of the public crisis information about the COVID-19 pandemic? and
- 2) What improvements do they suggest to enhance accessibility of public information in future societal crises?

## METHOD

### STUDY DESIGN

The study had a descriptive study design and involved qualitative thematic analysis (Braun and Clarke 2006) of data from interviews and focus group discussions complemented with statements and documents from disability rights organisations, and information concerning the pandemic from the websites of government agencies, healthcare regions, and local municipalities.

### PARTICIPANTS

We recruited people with impairments that, in accordance with the MTM definition, could affect the ability to perceive, retrieve and understand information regarding the COVID-19 pandemic, and to communicate about or understand how to act upon the information given. The MTM definition includes people who are blind or have low vision, people with reading and writing difficulties, people with mobility or hearing impairments, people with intellectual disability, and neurodiverse people. Moreover, we recruited individuals such as relatives, friends, or others who had assisted people with impairments in accessing, perceiving, or understanding information regarding the COVID-19 pandemic. The participants were recruited using snowball sampling by advertising in social media, and by contacts with disability rights organisations, as well as via the researchers' long-established network of contacts with disabled people. We also interviewed representatives from disability rights organisations. In addition, members of the Begripsam Group participated in validating and interpretive workshops to discuss the preliminary thematic analysis. The Begripsam Group is an action research community consisting of people with lived experience of impairments who are experts in accessibility. The researchers have established a close collaboration with the Begripsam Group in several previous research projects.

### DATA COLLECTION AND ANALYSIS

Data were collected during the autumn of 2021 by interviews and focus group discussions with people who have impairments and by interviews with relatives, friends, or other people who had assisted those with impairments during the COVID-19 pandemic. A semi-structured topic guide was used during interviews and focus group discussions, including two discussion themes designed to respond to the research questions of the study, namely: 1) How did people with impairments perceive the public information and communication in Sweden, that is, from the government, government agencies and the media, about the COVID-19 pandemic? and 2) How should public information and communication be adapted to be accessible in future societal crises and are there suggestions for improvements?

Two of the researchers (the second or third author) conducted the interviews and focus group discussions via telephone or online meetings using Zoom. The sessions lasted until the researcher sensed that additional information no longer generated new understanding (Patton 2015). The interviews lasted for 15–90 minutes, and the focus group discussions approximately 120 minutes including a break. The interviews and focus group discussions were recorded and

transcribed verbatim. A deaf research assistant conducted interviews and focus groups with deaf people in Zoom using Swedish Sign Language. The assistant then transcribed the interviews into Swedish text. The focus group format was considered favourable for promoting interaction and information exchange between the participants. Interaction allows the participants to respond to and build on the reactions of other participants in the group (Stewart, Hamdasani, and Rook 2009). However, we made it optional to participate by an individual interview if the participants preferred that instead of focus group.

In December 2020 and January 2021, qualitative thematic analysis with a semantic approach (Braun and Clarke 2006) was performed separately for each of the two research questions by the researchers (second, third, and fourth author). The researchers read the text files of the interviews and focus groups, and discussed the coding and interpretation. To increase trustworthiness in the interpretation of the data, the preliminary thematic analysis proposed by the researchers was reviewed, discussed and further elaborated in two validating and interpretive workshops (in January and March 2021) involving the researchers and members of the Begripsam Group.

To contextualise the participants' statements from the interviews and focus groups and to further deepen our understanding of the statements, the second and third authors visited the websites of the Swedish government agencies, healthcare regions, and local municipalities to check on information and communication regarding the pandemic. In addition, we also contacted disability rights organisations to collect statements and documents, that is, reports and debate articles, issued by the organisations to contextualise the participants' statements. This was done during the analysis process, and information from the websites and the disability rights organisations was added to the interpretation of the thematic analysis. The visited websites of government agencies were The Swedish Public Health Agency ([www.folkhalsomyndigheten.se](http://www.folkhalsomyndigheten.se)), The Swedish Civil Contingencies Agency ([www.msb.se](http://www.msb.se)), the official website for emergency information from Swedish authorities ([www.krisinformation.se](http://www.krisinformation.se)), and The National Board of Health and Welfare ([www.socialstyrelsen.se](http://www.socialstyrelsen.se)). In addition, websites of healthcare regions and local municipalities that were mentioned by the participants were also visited.

Preliminary results of the thematic analysis was published in a Swedish report advising government agencies on enhancing information and communication during the ongoing COVID-19 pandemic (Johansson, Forsell, and Gustavsson 2021).

In 2023, a researcher (first author) who had not been involved in any part of the previous analysis process, performed re-analysis of data. It confirmed the validity of the thematic analysis performed by the other researchers (second, third, and fourth author), (Patton 2015). The analyses were conducted using the text data analysis programme NVIVO (Lumivero, Release 14).

## **ETHICS AND CONSENT**

The study was approved by the Swedish Ethical Review Authority (Ref. No. 2020-04524 Decision date: 2020/05/Oct). A research assistant provided oral and written information about the study to the participants and the participants gave their written consent to participate prior to the study. When requested by the participants, the researchers conducting the interviews and focus groups provided additional information about the study. People with intellectual disabilities were informed orally by an easy-to-read text complemented with the use of pictograms from the official Swedish pictogram database (The National Agency for Special Needs Education and Schools 2019).

Prior to starting the focus group sessions, the moderator informed the participants about that the information provided would be transcribed and coded prior to analysis. In addition, the moderator requested the participants to adhere to confidentiality about what had been said by other participants during focus groups.

The involvement of the Begripsam Group in validating and interpretive workshops, concerned that they reviewed and discussed the preliminary analysis proposed by the researchers, which only contained pseudonymised material. Thereby they had no access to data from the interviews of focus groups that could have breached the principle of confidentiality.

## RESULTS

In total, 11 people participated in focus group discussions and 18 people preferred to be interviewed (Table 1). Furthermore, 19 people from the Begripsam Group participated in validating and interpretive workshops (Table 2). The results were organised in themes relating to the two research questions (Table 3). The first research question focusing on the perceived accessibility of public crisis information about the COVID-19 pandemic generated four themes. The second research question focusing on suggested improvements for enhancing the accessibility of future crisis information generated three themes. Below, we report our main findings from these themes, with some illustrative quotes and examples.

ID	IMPAIRMENT/ROLE	CHARACTERISTICS	DATA SOURCE
1	Aphasia, Stroke	Female, middle aged, living with family	Interview
2	Autism, Anxiety	Male, young, living alone	Interview
3	Parent to daughter with Intellectual disability	Female, retired, living with family	Interview
4	Blind	Female, middle aged, living with family	Interview
5	Blind	Male, middle aged, living alone	Interview
6	Blind	Female, retired, living alone	Interview
7	Blind	Female, middle aged, living alone	Interview
8	Low vision	Male, retired, living with family	Interview
9	Blind	Male, middle aged, living alone, having children living far away	Interview
10	Deaf	Female, middle aged, recently moved to Sweden, living with family	Interview
11	Deaf	Male, retired, living alone, having support from daughter	Interview
12	Deaf	Female, retired, living alone	Interview
13	Deaf, ADHD	Female, middle aged, living with family	Interview
14	Deaf	Female, middle aged, recently moved to Sweden as refugee, living with family	Interview
15	Blind	Female, middle aged, living with family	Interview
16	Support person for people with aphasia	Female, middle aged, living with family	Interview
17	Blind	Male, middle aged, living alone	Interview
18	Autism, ADHD, Epilepsy	Female, retired, living with family	Interview
19	Blind	Female, middle aged, living with family	Interview
20	Intellectual disability	Female, young, living with family	Interview
21	Intellectual disability	Female, young, living alone	Interview
22	Autism, ADHD, Depression	Male, middle aged, living alone	Interview
23	Low vision	Female, middle aged, living alone	Interview
24	Intellectual disability	Male, middle aged, living alone	Interview
25	Relative to a person with Autism	Female, retired, living alone	Interview
26	Aphasia, Stroke, Headache	Female, retired, living alone	Interview
27	Aphasia, Stroke	Male, middle aged, living with family	Interview
28	Deafblind	Female, retired, living alone	Interview
29	Low vision	Female, retired, living alone	Interview
30	Dyslexia	Male, young, living alone	Focus Group 1
31	Dyslexia	Female, middle aged, living with family	Focus Group 1

**Table 1** Participants in the interviews and focus group discussions.

ADHD: Attention Deficit Hyperactivity Disorders.  
 Age categories Young: ≤30 years, Middle aged: 31–64 years, Retired: ≥65 years.



ID	IMPAIRMENT/ROLE	CHARACTERISTICS	DATA SOURCE
32	Dyslexia	Female, retired, living alone	Focus Group 1
33	Dyslexia	Female, middle aged, living with family	Focus Group 1
34	Dyslexia	Female, retired, living alone	Focus Group 1
35	Dyslexia	Female, young, living alone	Focus Group 1
36	Project leader/Support person for Dyslexia, working in the disability movement	Female, middle aged, living alone	Focus Group 1
37	Project leader working with people with reading difficulties	Female, middle aged, living with family	Focus Group 2
38	Aphasia, Stroke	Female middle aged, living with family	Focus Group 2
39	Aphasia, Stroke	Female, retired, living alone	Focus Group 2
40	Intellectual disability	Male, young, living alone	Focus Group 2

ID	IMPAIRMENT/ROLE	CHARACTERISTICS	DATA SOURCE
41	Aphasia, Stroke	Female, middle aged	Validation workshop 1
42	Autism, Anxiety	Male, young	Validation workshop 1
43	Intellectual disability	Male, young	Validation workshop 1
44	Support staff to people with dyslexia	Female, middle aged	Validation workshop 1
45	Dyslexia, Dyscalculia, ADHD	Male, retired	Validation workshop 2
46	Dyslexia	Male, middle aged	Validation workshop 2
47	Hearing impairment	Female, middle aged	Validation workshop 2
48	Intellectual disability	Female, young	Validation workshop 2
49	Dyslexia	Male, retired	Validation workshop 2
50	Autism	Male, young	Validation workshop 2
51	Teacher in special education for people with intellectual disability	Female, retired	Validation workshop 2
52	Dyslexia	Female, young	Validation workshop 2
53	Brain fatigue	Female, retired	Validation workshop 2
54	Occupational therapist, specialised in cognitive impairments	Female, retired	Validation workshop 2
55	Dyslexia, Hearing impairment	Male, retired	Validation workshop 2
56	ADHD	Male, young	Validation workshop 2
57	Special educator for people with intellectual disability	Female, middle aged	Validation workshop 2
58	ADHD	Male, middle aged	Validation workshop 2
59	Support staff to people with autism	Female, middle aged	Validation workshop 2

RESEARCH QUESTIONS	THEMES
1. Perceived accessibility of the public crisis information about the COVID-19 pandemic	1.1 Usual information strategies and channels could be maintained during the pandemic
	1.2 Usual information strategies and channels were not maintained or disturbed during the pandemic
	1.3 Local public information about the pandemic was not presented in accessible formats
	1.4 The pace of publishing accessible information was not synchronised with the general information
2. Suggested improvements for enhancing the accessibility of future crisis information	2.1 Use multiple means for presenting public information
	2.2 Provide information at the same time and pace for everyone
	2.3 Be prepared and practice before the crisis

**Table 2** Participants in the validating and interpretive workshops.

ADHD: Attention Deficit Hyperactivity Disorders.  
 Age categories Young: ≤30 years, Middle aged: 31–64 years, Retired: ≥65 years.

**Table 3** Results of the thematic analysis on two research questions about perceived accessibility of the public crisis information and suggested improvements for accessibility of future crisis information.

## RESEARCH QUESTION 1: PERCEIVED ACCESSIBILITY OF THE PUBLIC CRISIS INFORMATION ABOUT THE COVID-19 PANDEMIC

In terms of the accessibility of crisis information, four themes emerged, namely (1) crisis information was perceived accessible by those who were able to continue using their regular information strategies and channels; (2) people experienced difficulties in accessing and understanding information because their regular strategies and channels were not maintained or disturbed during the pandemic; (3) local public information was perceived inaccessible, also by those who reported that the general information at national level was accessible; and (4) the pace of publishing accessible information was not synchronised with the general information.

### Theme 1.1: Usual information strategies and channels could be maintained during the pandemic

Many participants described that they had a preferred way to get important news. They also described that they could continue to use that way to get information about the COVID-19 pandemic. This is especially true for the information provided by the government and central government agencies on infection prevention. In short, this information asked the Swedish population to social distance, work or stay at home if possible and frequently wash their hands and to use hand disinfectant. Only later came recommendations on using masks.

Radio was one of the main sources of information during COVID-19. Participants who were blind often used radio as a primary source of information, and they could continue doing so during the whole pandemic. The Swedish Public Radio has a five-minute broadcast each day, with easy-to-understand news intended for people with intellectual disability and for people with Swedish as their second language. However, few of the participants reported that they had listened to those broadcasts.

Participants who got their news from television could continue watching and they often found the information from both media and government agencies accessible. For example, many participants with ADHD, autism and with reading impairments reported that they got information from watching television. The daily updates from government agencies, broadcast on television at two o'clock every day, was appreciated by many participants and became a standard routine for getting updated on the latest events, statistics, and recommendations. Swedish Public Television broadcast a daily five-minute news update in sign language. For the deaf participants this programme was well established, and many watched it. Some deaf participants found five minutes to be too short: 'they should have expanded the time...there are a lot of programmes with people talking all day, but we only got five minutes, that's not enough' (ID12).

Many of the participants, and especially people with ADHD and autism, also used online newspapers as a main source for information. Some used a function to subscribe to news alerts, distributed to their phones by text messages. A link directly to the news page triggered them to go to the newspaper. As one participant with autism said: 'When I pressed the link and read the specific news, it often happened that I read several other news items about COVID at the same time' (ID2).

Since the distribution of printed newspapers continued during the pandemic, participants who were used to reading a printed newspaper could continue to read. Participants with hearing impairments or dyslexia reported that newspaper was their preferred source of information about the pandemic. Also, some participants with intellectual disability reported that they read printed newspapers if someone could help them by reading out loud or explaining the news to them.

Some participants found that the crisis information was too exhaustive. One participant with ADHD said 'It is too much, every day... one hour on the news. I cannot concentrate so long. I cannot stand only listening to that' (ID18).

The government agency MTM used their ordinary list of subscribers to the 'talking newspapers' to send compiled information once a week, mostly to blind people. 'Talking newspapers' is a service where MTM converts over 100 Swedish newspapers to speech. This was appreciated by some of the blind participants, but most often they were already aware of the information since they listened to the radio.



Social media was not a primary source of information among the participants. Participants who reported having used social media had mostly visited established media resources on Facebook.

### **Theme 1.2: Usual information strategies and channels were not maintained or disturbed during the pandemic**

There were several reasons why participants could not maintain their usual strategies or use their regular channels for information. One main reason was that personal assistance was withdrawn as a protective measure to mitigate virus transmission. This was the case for deafblind participants who depend on tactile sign language, and often found that interpreters were not allowed to visit and assist them: ‘... communication is very much about being able to be close, not to have this distance’ (ID28).

Deaf participants found that sign language interpreters were not allowed to visit meetings and events where interpretation was needed. Many broadcast events were not texted or complemented with sign language interpretations. Participants with low vision reported that names, diagrams, and other figures used in television presentations were only presented visually and not complemented with audio descriptions.

Participants with intellectual disability and aphasia often depended on another person reading or explaining the news in a personal conversation, which was impeded by recommendations of social distancing during the pandemic.

I am unable to read. Typically, I attend church where there are people who read the news for me. The elderly residents in my building often help me by reading the news in exchange when I shop for them. However, that is not possible now (ID40).

A man with aphasia explained his strategy as ‘I hide at home, keeping away. My wife tells me what to do’ (ID27).

Participants who were deafblind, with reading difficulties or intellectual disability who were living alone, reported more problems with understanding the information. Those participants stated that they would have liked to discuss the public crisis information with someone, but since they isolated themselves, they missed someone to talk with and to reflect upon how to handle the information. In general, participants who reported that they were living alone more often reported problems handling the information than participants who lived together with someone.

Participants who could not continue to use their usual information strategies and channels often struggled to adapt to a new strategy. One of the most difficult things was to understand where to find information in formats they perceived accessible.

Participants with intellectual disability and aphasia reported that they needed easy-to-read information and also information augmented with pictures and symbols, but that kind of information was hard to find or completely missing. Participants with intellectual disability and aphasia also reported that television and radio presenters talked too fast, making it hard for them to digest all the information given. When we examined government agencies web pages, we found that one of the most central government agencies, MSB, The Swedish Civil Contingencies Agency placed their easy-to-read information and information in sign language under the menu ‘Other languages’ and none of the participants in our study had found that information.

While mainstream information on websites of government agencies often was updated on a daily basis, we found that the adapted information in many cases was not updated or updated with intervals of several months. It took a long time for the government agencies, healthcare regions, and local municipalities to produce a first round of accessible information. Then, this information was only updated sporadically or not updated at all.

The Swedish government and MSB once used the option to send a text message by phone to the whole population. But as one participant noted ‘that message did not include any links to further information, so it was hard to find more information’ (ID17).

Both Swedish Public Television and Swedish Public Radio have programmes for presenting news in an easy language and at a slower pace. These are five-minute programmes broadcasted each day. Participants with intellectual disability struggled more in understanding when the easy-to-understand newscasts were broadcast and on, for the radio programmes, on which channel. There is a special easy-to-read news magazine, printed and online, called 8Sidor (In English: 8 Pages) funded by the Swedish government. A few participants with intellectual disability used that magazine. But many people with intellectual disability were not able to follow this news medium without support from staff and since many activity centres were closed, there was no staff available.

### **Theme 1.3: Local public information about the pandemic was not presented in accessible formats**

Also those of the participants who reported that the general information at national level was accessible perceived that information coming from regional or local authorities was inaccessible. Almost all participants reported that when the information shifted from general information on how to mitigate the risk of virus transmission, to being specific to regional and local conditions, it also became more inaccessible. This coincided with the information also becoming more complicated. Information about how to be tested, the placement of local test sites and later on information on how, when, and where to get the vaccine, was rarely presented in accessible formats. In some healthcare regions, participants had to engage with both the region's online applications for healthcare information as well as the national portal for eHealth, just to understand how to book an appointment to get the vaccine. Some participants reported that they could not contact their local healthcare centre by any other means than by showing up in person at the centre, putting themselves and others at risk of transmission. The information provided with packages for home testing kits was found to be very complicated and presented with very small font sizes.

I have a severe vision impairment. I could not read that. My husband helped me. I wonder how people with low vision could read the instructions, fill in the forms (ID15).

A man with intellectual disability noted that local information was often missing:

It has been problematic with local information in my town. What should we do? And suddenly somethings have changed, and they don't explain why. For example, they closed the daily activity centres and banned visitors from our accommodated living quarters. But they did not explain why (ID24).

One participant with reading difficulties commented:

My region should have established routines for how to spread information acknowledging that people are different and need different ways to perceive information... Especially on how to take the test, book time for testing or how to meet healthcare staff (ID32).

One person with reading difficulties explained this as 'It was very hard to get detailed information. There was a lot of text with no read-aloud functionality' (ID31). This participant would have preferred to get local information by using a telephone number to a dedicated person to talk with to 'get stuff explained so that I could understand'.

One representative for a disability rights organisation noted that one of the healthcare regions' resource for augmented communication did produce accessible information that was also updated during the pandemic. We did note in our screening of websites that other actors linked to this content, but none of the participants in our study had seen this information.

In January 2021, we could only find one healthcare region that had updated their information with pictures to also cover vaccination, many did not have links to accessible information on their web start pages, and in many cases such information was missing.

Our screening of websites of local municipalities showed that they failed to provide accessible local public information about the pandemic. One exception was the city of Malmö. The city had already established routines and could regularly broadcast local updates about the

pandemic both in text and video. Videos were live texted and sign language interpreted. They also published weekly summaries in accessible videos.

#### **Theme 1.4: The pace of publishing accessible information was not synchronised with the general information**

Several participants expressed that accessible information was missing. In many cases this was a timing issue. When they needed the information, it was missing. Sometimes due to a slow updating pace for the accessible information and sometimes due to that no such information never was produced. A deafblind person reflected on the difficulties in reaching out to the government and making them understand that accessible information was missing: 'I think we have given up on them. It feels totally hopeless' (ID30). This participant also noted that many government agencies, the healthcare region, and local municipality stopped using text-telephone technology. Therefore, the participant could not use text messages to contact national telephone support resources for healthcare and crisis information.

After contacts between the Public Health Agency and the association for the Deafblind, the Public Health Agency recommended that interpreters should keep supporting deafblind people with interpretation, but many healthcare regions still had closed their interpreting support.

Disability rights organisations criticised the healthcare regions and the government agencies for not providing coordinated accessible information. Several representatives for disability rights organisations stated that public sector bodies seem to have been unprepared to systematically produce accessible crisis information. Disability rights organisations notified the government, government agencies, healthcare regions, and local municipalities that accessible information for their members was missing. One of the central government agencies, the Public Health Agency responded and improved, while most of the others responded very slowly or did not respond at all.

The Aphasia Association published a statement saying that: 'Government agencies must rethink their strategies and start to publish accessible crisis information. It is not an acceptable excuse to refer to "lack of time" when the WHO has declared COVID-19 to be a pandemic'. The association got an answer from the central government agency MSB, responsible for the official crisis information website, stating that they did not have any resources to publish accessible information. The MSB website was evaluated by the Dyslexia Organisation as being very inaccessible for their members since it was impossible to listen to text and that text was presented with poor layout and illogical structures.

In some cases, the disability rights organisations decided to produce accessible information with their own resources. The organisation for the Deafblind could not find any information explaining if deafblind people were in a risk group or not. Therefore, they hired an expert researcher to evaluate research publications and then used their own information channels to reach their members. Likewise, the organisation for people with intellectual disability, produced their own easy-to-read information complemented with pictures and symbols. An organisation for children with hearing and language impairments produced their own information material on how to avoid getting infected. Our screening of the government agencies websites confirmed the critique from the disability rights organisations and from the participants. We also found that government agencies, healthcare regions and local municipalities sometimes linked to information produced by a disability rights organisation, rather than producing their own information. For example, the MTM, and the Swedish Agency for Participation (MfD) tried to compensate for the difficulties in finding accessible information, by collecting useful links and presenting them on their own websites. However, no participant in our study had found this information.

MfD, which is the government agency with responsibility to provide for enhanced accessibility, tried to promote publication in accessible formats by presenting guidance for information providers. MfD compiled a webpage with recommendations on how to produce accessible information. MTM presented a webpage with guidance on how to write easy-to-read text. The Institute for Language and Folklore (Isof) created advisory material on accessible information but also multilingual information. The Isof also emphasised everybody's right to information in blog-postings and web pages and actively contacted government agencies in an attempt to

provide guidance in producing accessible information. The National Agency for Special Needs Education and Schools, SPSM, produced pictogram-based information and also a video with animated pictograms.

Our screening of government agencies websites showed that the publication pace of adapted information was slow. While the general information was updated on daily or weekly basis, the adapted information could remain un-updated for weeks or months.

## **RESEARCH QUESTION 2: SUGGESTED IMPROVEMENTS FOR ENHANCING THE ACCESSIBILITY OF FUTURE CRISIS INFORMATION**

In regard of how to improve accessibility of future crisis information three main themes emerged, namely: (1) using multiple means for presenting public information will allow people to find a way to get crisis information that is accessible for them; (2) accessible crisis information must be published at the same pace as other crisis information; and (3) strategies for accessible crisis information need to be prepared and tested before the crisis.

### **Theme 2.1: Use multiple means for presenting public information**

Public crisis information presented in written, oral and audio-visual forms should be the basis for any crisis information. Most people with impairments can use one of these to remain informed during a crisis. Nevertheless, there are people who need more than this. Participants in this study proposed that simplified versions of text, oral or audio-visual content is needed. Information in text, especially simplified text, needs to be augmented by pictures or symbols. Participants also proposed that interpreters must be engaged.

Another suggestion by the participants was that some would have preferred to receive written letters sent to them through the postal services. Some people would always need another human to prioritise the information, but also to explain what the information means and what it suggests you should do.

The speed of presenting vital adapted information needs to be adjusted. Some deaf participants noticed the sign language interpretation was going too fast. Probably because the interpreter was trying to keep up with the pace of the spoken presentation:

I would like to receive information in slow sign language, calmly, that they speak slowly (ID14).

Many of the participants called for the use of well-known techniques for the transformation of information from one modality to another. That is, to use technology for transforming text to speech or text to braille. They also called for the use of human interpreters transforming spoken Swedish to Swedish sign language. When spoken language is broadcast it should be texted and if important information in audio-visual content is presented as images, tables, and graphs it should be complemented with audio descriptions.

Some people need a trigger to spark an impulse to get information. The technique used by commercial online newspapers, who send text messages with clickable links, is also suggested for use by the government and the government agencies.

Deaf participants proposed that the regional centres for sign language interpreters should be used as hubs for public crisis information in sign language. That is, when put in a crisis mode, the centres could shift from serving as interpreters to also act as information providers. The same goes for libraries and churches that could be used as hubs for people who need the information to be explained to them by other humans. Deaf and deafblind participants also wanted to be able to use text messages for direct communication with a national telephone number for crisis information.

A blind participant noted that when media broadcast interviews where people were interviewed in English, there were subtitles in Swedish. It was not possible to read the subtitles with assistive technology; hence the interview was inaccessible for a blind person who does not understand English. The participant knew that there is a technique for 'speaking subtitles' but stated: 'the technology is there, but they don't use it' (ID5).

## Theme 2.2: Provide information at the same time and pace for everyone

Every crisis has its own rhythm. Sometimes public information needs to be updated fast and frequently and sometimes the pace can be slower. The participants in this study emphasised that regardless of your difficulties to perceive and understand information you need the information at the same time as everybody else.

If possible, it is a good idea to bring predictability into the presentation of crisis information. Having daily updates at the same time with the same central persons on stage created a familiar format and the participants appreciated that. Likewise, the specially adapted information should be presented in the same predictable way and if needed, extended beyond the ordinary five minutes a day. A deaf person suggested:

I think there's too little information... they should expand it.... Now during corona they should broadcast more, not just five minutes' (ID13).

## Theme 2.3: Be prepared and practise before the crisis

The participants pointed out that every actor with an information role in a crisis should be prepared to provide accessible crisis information. Depending on the nature of the crisis, there will be different stakeholders involved. Being prepared also concerns the fact that individuals with impairments may need access to online services and training in the ability to use them. This was expressed by several participants who claimed that with more training they could have used online information channels more easily:

People with low vision should be offered more training in how to use computers, smartphones, web pages etc... This should be provided by the Centres for low vision in the healthcare regions, ...but they only provide very limited education or no education at all (ID6).

Participants also pointed out that important societal services such as libraries, centrals for interpreters, and centrals for escorting services, need to be maintained and not shut down during a crisis.

Representatives from the disability rights organisations advocated for improved collaboration between governmental agencies, healthcare regions, and local municipalities to ensure the provision of accessible crisis information from the onset of a crisis. They suggested that central actors should have established routines for regular evaluations in cooperation with the disability rights organisations to ensure that the information is perceived as accessible and that it reaches their members in time. The chair for the Aphasia organisation communicated that authorities need to take a major step and start offering crisis information in the form of easy-to-read texts, with short, subtitled videos and using image support.

Engaging people with impairments in the production cycle would create an opportunity to make quality improvements before vital information is published. A participant from The Dyslexia Organisation reported that their members evaluated the three most central information websites and found problems with layout, structuring of texts, problems with search engines and lack of text to speech functionality; however, the government agencies responsible for the central websites did not react in response to this information.

## DISCUSSION

This study showed that society exhibited shortcomings in providing accessible information to people with impairments in Sweden during the COVID-19 pandemic. The United Nations identified accessible information as a key to protect citizens during the COVID-19 pandemic (United Nations 2020). Recommendations have stated that accessible information should be produced with high quality, be timely, and be updated and provided both in detail and breadth (Meltzer 2020). However, it is notable that several of the responsible authorities seemed to be unprepared prior to the pandemic for disseminating accessible information. Even though supporting government agencies collated information on how to produce accessible information and with complaints from disability rights organisations this did not result in any significant improvements during the crisis. Anyone interested in how to produce and distribute accessible

information can easily find guidelines, tutorials, and if needed, experts that can provide training and support to establish production and publication routines. The lack of accessible crisis information cannot be explained as a lack of how-to knowledge and the problems with inaccessible crisis information have been noted before (Fernández-Díaz et al. 2020; Gleason et al. 2020; Meltzer 2020). This points to a general and well-known problem of information being inaccessible for people with impairments (Johansson, Gulliksen, and Gustavsson 2021; Meltzer 2020). Jonathan Lazar has introduced the concept of 'Born Accessible' to argue that accessibility should not be bolted on afterwards but rather be an initial quality already from the first publication of information (Lazar 2023). Such approach is never more important than during a crisis. Time is a critical factor in a crisis. To give some parts of the population access to vital information much later than others would be unfair and potentially very dangerous. Nevertheless, this is what seems to have happened. Studies of web accessibility (Acosta-Vargas et al. 2022; Alismail and Chipidza 2021; Ara and Sik-Lanyi 2022; Dror et al. 2021) and studies of readability (Mac et al. 2021; Valizadeh-Haghi, Khazaal, Rahmatizadeh 2021; Worrall et al. 2020; Wrigley Kelly et al. 2021) found that almost all crisis information during the pandemic did not comply to accessibility standards and was difficult to understand.

The government, applicable government agencies, healthcare regions and local municipalities should have routines in place and have the required skills, either in-house or procured from third-party providers. All those stakeholders have important information to provide to the whole population in crisis and non-crisis modes. If the production and distribution of accessible information was part of usual routines, it would be easier to maintain within the same routines during a crisis. When the crisis is a fact, it is too late to start developing skills and establishing routines to also reach the population in need of adapted and accessible information. Providing opportunities for human assistance needs to be acknowledged as a vital part of a strategy for providing accessible crisis information and to be an integral part of the crisis information strategy. In addition, for crisis information to be equally accessible for all citizens, it should be acknowledged that some people with impairments needs more, and sometimes very specific information, to be in an equal position to people without impairments. One example is the deaf blind people who did not even know if their diagnoses put them in a risk group. Thus, routines for accessible information provision should accommodate for a wide range of needs.

There is extensive knowledge in the disability rights organisations and among their members on how the crisis information reaches or does not reach their communities. This could be used by authorities to disseminate if the information is perceived accessible and understandable, but we have found no such organised cooperation. Instead, organisations feel they have been ignored and that their complaints did not result in updated routines or changes in how the production of information was organised.

We argue that the problems the participants report, must be understood as a form of discrimination. A specific form of discrimination is ableism, the assumption that everyone is able-bodied and also that an able body is superior to a disabled body (Campbell 2008). As argued by Johansson, 'To acknowledge human diversity is often easy as a principle, but in practice it is common to instinctively fall back into what unconsciously is considered to be normal' (Johansson 2019). A similar view can be found in audism, the discriminatory thinking that deaf people are inferior to hearing people (Lane 1992). To provide able-bodied citizens with COVID-19 information that they could access while leaving people with impairments behind must be seen as discrimination and a failure to protect all citizens during the crisis.

## **STRATEGIES FOR ENHANCING ACCESSIBLE INFORMATION IN A FUTURE SOCIETAL CRISIS**

The most important action for any stakeholder providing crisis information and communication is to use already known principles for accessibility and to apply this knowledge in the ordinary information production. That would make the transition to crisis information mode seamless regarding accessibility. In addition, this study highlights that when moving to crisis information mode the following aspects need consideration in order to ensure accessible information provision:



- Ensure predictability and structure in information provision by publishing information in predictable places and at predictable times.
- Government, government agencies, healthcare regions, local municipalities and other actors responsible for the provision of crisis information and media ought to train in advance, and establish routines for producing and publishing accessible crisis information.
- Improve collaboration between the disability organisations, governmental agencies, region authorities, and local municipalities to ensure the provision of accessible crisis information from the onset of a crisis.
- Accessible crisis information should be published and updated at the same pace as mainstream information.
- Information should be provided in a mix of different types of accessible formats and distribution channels such as easy-to-read text, easily presented oral information, images to support written text, and information in sign language.
- Push notifications should be used to create an incentive to update oneself on the latest information, for example by use of text messages sent to the smartphone with a link to a webpage with updated information.

## STRENGTHS AND LIMITATIONS

To increase trustworthiness of this study, quality criteria for qualitative studies outlined by Alvesson and Sköldbberg (2018) and Lincoln, Guba, and Pilotta (1985) were considered; credibility, dependability, confirmability, and transferability.

It is a strength of this study that we applied a robust methodological approach by performing the qualitative thematic analysis in a stepwise procedure. The interviews and focus group discussions generated rich information. Confirmability of data and credibility of the findings from interviews and focus groups were strengthened in that the preliminary thematic qualitative analysis was further elaborated and validated in workshops with the target population (the Begripsam Group). In addition, we contacted disability rights organisations to collect statements and documents and we screened websites of government, government agencies, healthcare regions, local municipalities and media to confirm interpretation of data collected at interviews and focus group discussions. To further increase the dependability of data and trustworthiness in the interpretation of the data, a reanalysis was conducted involving an additional researcher.

The small sample size and the qualitative nature of data collection and analysis limits interpretation of transferability of the findings. Still, we believe the purposeful sampling approach aimed at including participants representing a wide range of all relevant impairments was achieved, which strengthened the possibility of transferring the findings to other people with the same impairments. Further, we suggest that the findings might to some extent be transferable to people who have Swedish as second or third language. Immigrants living in Sweden could plausibly also benefit from easy-to-read information and from text being complemented with pictures. However, caution should be made in generalisation of the findings to other countries since the context in Sweden might differ to other countries.

## CONCLUSIONS

This study adds to earlier research by showing that the regional and local information was often perceived as the most inaccessible. Many people with impairments relied on old-school technology and thereby used other strategies for accessing information than relying on website information. Some of society's measures to mitigate the pandemic, such as closing libraries, churches and other local information-hubs in the municipality, caused severe problems for people who are dependent on other people to understand crisis information.

This study showed that several of the authorities who were responsible for providing public information on the COVID-19 pandemic in Sweden seem to have been unprepared to provide information that was accessible to all citizens. It is suggested that proactive planning and training are imperative to ensure the provision of accessible information when a societal crisis occurs. Every citizen needs information at the same time to be able to act wisely and to protect themselves or others. People with impairments need information that they can access and

understand no later than any other citizen. Central government agencies should be particularly well prepared to produce accessible crisis information, disseminate it effectively, and support less experienced producers of accessible crisis information.

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## COMPETING INTERESTS

The authors have no competing interests to declare.


## AUTHOR CONTRIBUTIONS


The second and third authors were responsible for all data collection. Second, third and fourth authors produced the first thematic analysis that resulted in the report to the government agencies. First, second and fourth authors was jointly responsible for drafting the text of the manuscript. All authors contributed to the final version of the manuscript and have approved its publication.

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