Design opportunities for future development of crisis communication technologies for marginalised groups – Co-designing with Swedish disability organisations

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Abstract

Purpose – The purpose is to firstly, provide an example of how voices of people with various disabilities (motor, visual, hearing, and neuropsychiatric impairments) can be listened to and involved in the initial phases of a co-design process (Discover, Define). Secondly, to present the outcome of the joint explorations as design opportunities pointing out directions for future development of crisis communication technologies supporting people with disabilities in building crisis preparedness. The study was conducted during the Covid-19 pandemic.

Design/methodology/approach – The study assumes a design research approach including a literature review, focus group interviews, a national online survey and collaborative (co-)design workshops involving crisis communicators and representatives of disability organisations in Sweden. The research- and design process was organised in line with the Double Diamond design process model consisting of the four phases: Discover, Define, Develop and Deliver, whereof the two first phases are addressed in this paper.

Findings – The analysis of the survey data resulted in a series of challenges, which were presented to and evaluated by crisis communicators and representatives from the disability organisations at the workshops. Seven crisis communication challenges were identified, for example, the lack of understanding and knowledge of needs, conditions and what it means to build crisis preparedness for people with disabilities, the lack of and/ or inability to develop digital competencies and the lack of social crisis preparedness. The challenges were translated into design opportunities to be used in the next step of the co-design process (Develop, Deliver).

Originality/value – This research paper offers both a conceptual approach and empirical perspectives of design opportunities in crisis communication. To translate identified challenges into design opportunities starting with a “How Might We”, creates conditions for both researchers, designers and people with disabilities to jointly turn something complex, such as a crisis communication challenge, into something concrete to act upon. That is, their joint explorations do not stop by “knowing”, but also enable them to in the next step take action by developing potential solutions for crisis communication technologies for facing these challenges.

Keywords Co-design, People with disabilities, Covid-19 pandemic, Crisis communication technologies, Design opportunities, Disability organisations

Paper type Research paper

Introduction

The Covid-19 pandemic has resulted in changed life conditions across the globe. People have been faced with locked down societies, strained health care and all sorts of measures to mitigate the virus from spreading. Besides these direct effects, the pandemic situation has also revealed gaps in general crisis preparedness and weaknesses, which ought to be addressed to ensure that...
we are better prepared for future crises, whatever they might entail (Eriksson et al., 2021; Lundålv et al., 2022). To achieve crisis preparedness, it is important that all people are included and involved and that crisis communication is designed in such a way that everyone can interpret it and understand how to adapt the rules and recommendations to their life situations.

The research project presented in this paper, aims to explore and co-design communication methods and technologies for supporting crisis preparedness (Eriksson et al., 2021; Lundålv et al., 2022). The focus is on marginalised groups and people with disabilities not included in the normative assumptions of general crisis communication (Coombs and Holladay, 2012). At an early stage in our project, it became apparent that there are groups that are more difficult to reach and communicate with in the event of a crisis, such as people with various disabilities and who are dependent on extra support and help (Lundålv et al., 2021). The study also revealed the need to more carefully listen to the voices of people with disabilities and involve them in designing crisis communication technologies aimed at strengthening their crisis preparedness (Lundålv et al., 2021). Crisis communication technologies are here referred to as technologies that are used to access, understand, interpret, evaluate and act upon crisis information provided (Coombs and Holladay, 2012).

Consequently, as part of our project we set up a collaborative (co-)design process and invited Swedish disability organisations representing people with motor, visual, hearing and neuropsychiatric impairments, to be part of a co-design workshop remotely conducted in online settings. The aim of the workshop was to create an understanding of the challenges that the members of these disability organisations are facing in terms of accessing, understanding, interpreting, evaluating and acting upon crisis information made available through different communication technologies, such as, e.g. websites, national and international news media, and social networks. Based on this, a collection of design opportunities was identified for future development of crisis communication technologies supporting people with various disabilities in navigating through the crisis information provided by authorities, but also other channels via friends, caregivers and media.

Prior to the co-design workshop, focus group interviews, a national online survey and a preparatory workshop with crisis communicators were conducted (Eriksson et al., 2021; Lundålv et al., 2022). The results of these interventions revealed a complex crisis communication landscape. In a contemporary digital society, crisis information is no longer about one message being sent via public channels speaking to the public about how to act and live in a crisis. Instead, the public are accessing multiple channels and listening to multiple voices and messages sent nationally and internationally and not seldomly pointing in different directions. Not only the channels and messages are numerous, but also the target groups that are to receive, interpret and act on the crisis information provided. The results also revealed a lack of social crisis preparedness. The disability organisations that contributed to the national online survey reported that some of their members have suffered from loneliness and isolation during the Covid-19 pandemic, which leads to more vulnerable situations and less independence. This applies especially to marginalised groups, who in their social life make use of various institutional support functions that run the risk of disappearing in crisis situations.

As argued in critical disability studies, people with disabilities are “made” disabled since society is not capable of accommodating their needs nor open to alternative ways of being, acting and living (Lyngbäck et al., 2020; Kilman et al., 2021). When relevant support is offered to people with disabilities, they can act and live a life without disabling barriers. The term “disabled people” is used by disability organisations in their strive to realise social rights and to remove such problems and barriers (Charlton, 1998). Disability organisations possess extensive knowledge and experience that is important to include in both disability research and social policy research (Priestley et al., 2010; Shakespeare et al., 2022).

Aims and research questions

The aims of this research article are to firstly, provide an example of how voices of people with various disabilities (motor, visual, hearing and neuropsychiatric impairments) can be listened to and
involved in a collaborative (co-)design process remotely. Secondly, to present the outcome of the joint explorations as design opportunities pointing out directions for future development of crisis communication technologies supporting people with disabilities in building crisis preparedness.

The research questions explored are:

**RQ1.** How can the experiences of people with various disabilities be taken into account and addressed in the first phases of a co-design process conducted remotely?

**RQ2.** What design opportunities for future development of crisis communication technologies are identified based on the insight generated from the joint explorations?

The first question is answered by presenting a detailed description of how the two first phases of the co-design process were organised and conducted. The second question is answered by presenting the series of crisis communication challenges that were identified by analysing the data being generated through the joint explorations and the design opportunities formulated based on these challenges.

**Background**

Crisis can be seen and understood as a hazardous event or decision making that can present itself both as danger and opportunity (Trevithick, 2020). During times of crisis, such as the Covid-19 pandemic, daily needs may become challenges, social functions and infrastructures can cease to operate. Trust in governance risks diminishing and it can become challenging to find reliable information. This makes responding to a crisis challenging and especially for those who in their social life make use of various institutional support functions and who are not included in the normative assumptions of general crisis communication, such as people with disabilities (Lundalv et al., 2022; Lyngbäck et al., 2020).

**Co-designing crisis communication technologies**

The design process presented assumed a collaborative approach by inviting disability organisations to be part of joint explorations in the initial two phases of a co-design process aiming at exploring crisis communication technologies used to access, understand, interpret, evaluate and act upon crisis information (Coombs and Holladay, 2012) and through that achieve crisis preparedness. This approach goes in line with previous research in the field of disaster informatics and emergency management that stresses the need of empirical research from a user-centred perspective to inform and develop communication tools and strategies to use in emergency situations (Palen et al., 2014; Tomlinson et al., 2013). Such a user-centred approach is the foundation of participatory design putting an emphasis on the ethical standpoint that those affected by design ought to have a say in the design process (Simonsen and Robertson, 2013). Instead of designing for the users, the designers and/or researchers co-design with the users in a process of joint decision-making, mutual learning and co-creation (Sander and Stappers, 2012). This approach improves the chances of achieving a design that really meets the needs of people with disabilities since they have contributed to developing it.

**The Double Diamond design process model**

The co-design process was organised in line with the Double Diamond design process model (Design council, 2021). The model provides a comprehensive visual description of an iterative design process consisting of the four phases: Discover, Define, Develop and Deliver (Figure 1).

The first phase in the model (Design council, 2021), Discover, is about creating an understanding of the current state of the field and pinpointing problems and opportunities. In the second phase, Define, the insights generated are gathered, reviewed and narrowed down to identify challenges of relevance to address. A useful approach to make sense of the findings is to reframe the challenges
as “How Might We” questions to turn them into design opportunities (IDF, n.d.). In the Develop phase, the design opportunities are explored together with the stakeholders through design-oriented activities in workshop settings. In the last phase, Deliver, the outcome of the previous phase is evaluated and reflected upon and the results of the project are presented.

Methods

The two first phases of the co-design process are reported upon: Discover and Define (Figure 1). The methods applied in the first phase were focus group interviews, a national online survey and a literature review. In the second phase, a preparatory workshop with crisis communicators and a co-design workshop with disability organisations representing people with motor, visual, hearing and neuropsychiatric impairments were organised.

Data gathering and analysis

Phase I: discover. The first step of the co-design process aimed at gaining an understanding of the crisis communication challenges that crisis communicators and people with various disabilities faced during the Covid-19 pandemic. The methods used were focus group interviews (Denscombe, 2019), an online survey (Robson, 2011) and a literature review (Denscombe, 2019).

Three focus group interviews (each 1.5 h long) were conducted with representatives from a civil society organisation (two respondents), the Swedish Civil Contingencies Agency (two respondents) and three municipalities (three respondents), all working with crisis communication targeting people with disabilities. The interview with the civil society organisation was conducted in their studio space. The interviews with Swedish Civil Contingencies Agency and the municipalities were conducted online using a video conferencing program. An interview guide was used. The interviews were audio recorded and transcribed verbatim. A thematic analysis of the transcripts was conducted where themes that represent recurrent and distinctive features of the respondents’ experiences and perceptions were identified (King et al., 2019). The identified themes served as guidance when designing the online survey.

An online survey consisting of 17 questions were sent to crisis communicators at municipalities and to representatives of disability organisations distributed across Sweden. A total of 38 responses
were collected from the crisis communicators and 62 responses from the disability organisations. The questionnaire responses were analysed through a SWOT (Strengths, Weaknesses, Opportunities, Threats) analysis (Jackson et al., 2003). The analysis resulted in identified communication challenges that in the second step were categorised and described as the main crisis communication challenges.

The literature review aimed at creating an overview of relevant research in the field with a focus on how people with disabilities handle the pandemic. A literature search was carried out using several different international databases (Web of Sciences, Scopus, PubMed and Google Scholar).

The results emerging from the activities were brought together, summarised and resulted in seven identified crisis communication challenges. They served as a point of departure to in the second phase, Define, narrow down the scope of the explorations and identify the challenges of most relevance to address.

Phase II: define. Two remote workshops were conducted in online settings using a video conference program and a joint digital whiteboard for sharing and adding visual materials, notes etc. The discussions were documented on the digital whiteboard and audio recorded.

The first workshop, referred to as a preparatory workshop involving four crisis communicators, aimed at presenting and evaluating the results of the previous phase and planning the co-design workshop with the disability organisations. The participants were introduced to the outcome of the literature review and the seven crisis communication challenges (more in detail described in the Results chapter):

1. Lack of understanding and knowledge of needs, conditions and what it means to build crisis preparedness for people with disabilities,
2. Lack of and/or inability to develop digital competencies,
3. Lack of social crisis preparedness,
4. Lack of communication with marginalised groups,
5. Difficulties in reaching out to people with no access to digital media,
6. Insufficiently adapted messages,
7. Lack of access to dialogue methods to create an understanding of the peoples’ various needs, situation, behaviours and conditions.

The challenges were reframed as design opportunities that the workshop participants reflected upon and evaluated. This resulted in a deepened discussion on the communication challenges identified and in particular the challenge of navigating through a complex crisis communication landscape of a contemporary digital society. The workshop resulted in a revised list of crisis communication challenges, summaries in two overarching themes Crisis preparedness also including components of crisis communication literacy and social crisis preparedness and Communication/dialogue methods creating conditions for dialogue between authorities and the public, but also methods for how different target groups can participate in designing crisis communication directed towards them. The list of design opportunities was re-formulated based on the new findings.

The second workshop, referred to as a co-design workshop with disability organisations, aimed at creating an understanding of how members of the organisations have experienced and coped with the Covid-19 pandemic and what difficulties but also opportunities they may have encountered. As was shown in the previous activities, there is a need to increase the social crisis preparedness to prevent loneliness and isolation during crises. This applies especially to those whose social life is dependent on various institutional support functions that risk disappearing in crisis situations. Based on these insights, the second workshop focused on the topics of Crisis communication and Social crisis preparedness.
The co-design workshop consisted of three exercises. The first exercise began with an introduction to the topic of crisis communication and the complexity of today’s crisis communication landscape. The workshop participants were divided into two groups and asked to describe how members of the disability organisations access, interpret, evaluate the crisis information and take subsequent action based on this.

The data generated from their discussions were categorised in four themes

1. Sources/channels: where and how do they access crisis information?
2. Source criticism: how do they evaluate and judge whether the sources are reliable?
3. Comprehension: is the crisis information difficult to understand or interpret?
4. Action: what are the measures taken based on the crisis information?

The themes created the basis for a description of how the members navigate through the complex landscape of crisis communication and specific crisis communication challenges related to that.

The succeeding two exercises dealt with the topic of social crisis preparedness and how the members coped with the pandemic situation. The workshop participants were re-grouped in three groups and given the task of creating a fictional character (name, age and gender) that would represent a typical member of the disability organisations. To firstly get an idea of the members’ situations before the pandemic and what life was like then, they created an annotated, visual timeline where they briefly described their characters’ lives before the outbreak. On the timeline they added activities in the morning, during the day, in the afternoon, in the evening and during the night.

The last exercise aimed to create an understanding of their characters’ lives during the Covid-19 pandemic. By taking point in departure in their characters’ lived experiences and situations, the workshop participants were asked to discuss:

1. What have been easier, or more difficult as usual,
2. If/how they have received more or less help and support during the Covid-19 pandemic.

The generated data was analysed through a SWOT analysis (Jackson et al., 2003). The answers were sorted under the four factors (strengths, weaknesses, opportunities, threats), which created themes of insights that were analysed through theories of coping and coping strategies (Lazarus and Folkman, 1984). The analysis contributed to creating an understanding of what coping strategies people with various disabilities have used to adapt to different situations during the pandemic. Such situations involve difficulties of absorbing crisis information and sorting the different messages given by the authorities due to, for example, fatigue and limited capacity and concentration difficulties curtailed their accessing information even if it was freely available via various crisis information technologies. “Information fatigue” in this case is not only caused by an overload of information, but also by their individual conditions for partaking.

The outcome of the co-design workshop generated insights into how members of the disability organisations have coped with the Covid-19 pandemic and specifically regarding the challenges of crisis communication and social crisis preparedness. The findings were used to revise the identified crisis communication challenges and to iterate upon the design opportunities leading to the next phase, Develop, which aims at developing potential solutions for crisis communication technologies for facing these challenges. The execution of the co-design workshop also generated new insights on how to organise collaborative and remote workshops in online settings and how to create conditions for everyone to partake.

Respondents

The respondents (6 women, 2 men) partaking in the three focus group interviews and the preparatory workshop with crisis communicators represent a civil society organisation, 3
municipalities and the Swedish Civil Contingencies Agency. All respondents are partners of the Norm-creative crisis preparedness project (RISE, n.d).

The online survey was distributed to crisis communicators at 49 municipalities and to representatives of 59 disability organisations, whereof 38 crisis communicators (28 women, 9 men, 2 gender not specified) and 62 representatives from the disability organisations (40 women, 20 men, 2 gender not specified) responded.

The 10 respondents (6 women, 4 men) partaking in the co-design workshop came from disability organisations primarily representing people with motor, visual, hearing neuropsychiatric impairments. The representatives are elected by the members of their organisations and serve as their voice in the public sphere. The respondents were recruited by sending an invitation to the 49 organisations included in the umbrella organisation the Swedish Disability Rights Federation (Funktionsrätt Sverige, 2017). The selection of organisations should not be seen as a representative selection of the disability organisations that exist, but a selection based on the interests and availability of the organisations.

Research ethics and ethical considerations

All research activities assume research ethics principles as outlined by the Swedish Research Council (2017) and the General Data Protection Regulation act (GDPR.EU, 2021). Prior to the workshops, the participants were informed about the purpose of the present study, its approach and methods for handling data. Oral and written informed consent was achieved. Specific ethical considerations and awareness are required when conducting research involving people with disabilities (Beauchamp and Childress, 2013; Miller and van Heumen, 2021). At the co-design workshop, no individual data was gathered since the workshop participants were representing the members of the disability organisations and thus participated on a general level (organisational level). Individual conditions were not directly studied and the results presented address concerns on a societal level and on an aggregate level. Therefore, no application for traditional ethical approval was submitted and the study did not undergo an ethical review.

Results

How can the experiences of people with various disabilities be taken into account and addressed in the first phases of a co-design process conducted remotely?

As described in detail in previous sections, the experiences of people with disabilities were listened to and considered throughout the two initial phases of the co-design process conducted as part of our project (see Figure 1). To summarise, the co-design process, structured in line with the Double Diamond design process model (Design council, 2021) started with a research phase, Discover, aiming to go from the project’s general problem statement to specific crisis communication challenges of relevance to explore. To generate data for a broader selection of respondents, a national online survey was distributed to both crisis communicators developing crisis communication targeting people with disabilities and to disability organisations. Focus group interviews were conducted with crisis communicators to understand which questions of relevance to include in the online survey study. The analysis of the online survey data resulted in a series of identified crisis communication challenges. During the workshop activities conducted as part of the co-design process, the crisis communication challenges were revised and evaluated, either by the crisis communicators or by the representatives from the disability organisations. Simultaneously, the design opportunities taking point of departure in the crisis communication challenges, were revised and evaluated.

The co-design workshop settings created conditions for the participants to share their social and collective experiences by translating their thoughts into actions. The workshop activities allowed them to articulate, translate and materialise their experiences and viewpoints into different forms of articulations (e.g. the fictional characters taking action, the timelines) in a process of reflection-in-
action (Schön, 1984). That is, the sharing of experiences was facilitated by the joint workshop activities, which enabled and fostered inclusion and participation and provided a form of connection between the participants. The framing and re-framing of problems or challenges were not done solo by one person, but in a reflective conversation between all involved. Since the workshop was conducted during a pandemic outbreak, the participants expressed a great need to share experiences and to socialise. This became evident during the conversations and interactions characterised by reciprocity and openness.

The final list of design opportunities presents concrete design briefs to work within the forthcoming step of the co-design process, Develop (not elaborated upon here), which aims at developing potential solutions for crisis communication technologies tackling these challenges. As made visible in the detailed descriptions of the workshop activities included in the co-design process, the voices and experiences of people with disabilities were continuously taken into account. The development of key findings became an iterative process, which consisted of refining and improving the list of design opportunities based on new insights gained.

Such an approach, that is, taking the voices of people with disabilities into account throughout the whole process iteratively, increases the chances of achieving a design that really meets their needs and the challenges that they are facing. To translate identified challenges into design opportunities starting with a “How Might We”, creates conditions for both researchers, designers and people with disabilities to jointly turn something complex, such as a challenge, into something concrete to act upon. That is, their joint explorations do not stop by “knowing”, but also enable them to in the next step to take action by developing potential solutions for facing the challenges.

The strategy chosen to get access to the voices and experiences of people with disabilities was to go via representatives of disability organisations and ask them to channel their voices. The representatives’ contributions were based on knowledge acquired from a broad and long-term engagement with their respective members, of whose interests they are also spokespersons. Involving this group of people who are referred to as a marginalised group, but through representatives open for other types of collaborative settings, which otherwise might not have been possible due to ethical and practical reasons. The disability organisation representatives can anonymise and compound the experiences from their members in a way that would not have been possible if the research was focused on individual experiences.

What design opportunities are identified based on the insight generated from the joint explorations?

The design opportunities developed are based on the crisis communication challenges identified, evaluated and iterated upon throughout the two first phases of the co-design process. The design opportunities aim at pointing out directions for future development of crisis communication technologies targeting people with disabilities, but without anticipating which solution to go for yet. That is, the design opportunities formulated as “How Might We” questions open up a design space that allows for creative explorations and openness towards new ideas, but still point out a clear direction for potential next steps grounded in the findings. Before presenting the design opportunities, the seven identified crisis communication challenges are here briefly described:

1. Lack of understanding and knowledge of needs, conditions and what it means to build crisis preparedness for people with disabilities

Among people with disabilities, there is great individual variation in needs and conditions, which makes it difficult to start from general crisis plans on how to achieve crisis preparedness. Information is also lacking about what the members’ rights are and what support they are entitled to, but also what their obligations and personal responsibilities are as well as how to best communicate needs. Further on, authorities, municipalities and companies also lack knowledge about their conditions, how to meet their needs and how they are affected during crises.
(2) Lack of and/or inability to develop digital competencies

A significant part of the members of the disability organisations has low levels of digital competencies. Many of them do not have access to digital platforms and video conferencing programs (e.g. Zoom Video Communications, Microsoft Teams) and can therefore not participate in digital meetings, teaching, annual general meetings, etc. Lack of digital access also creates obstacles in everyday life due to digital interactions with municipalities and government agencies requiring e-identification, for example to collect paperwork and apply for grants.

(3) Lack of social crisis preparedness

Many members of the disability organisations have suffered from loneliness and isolation during the pandemic. This leads to increased marginalisation and they become less independent. In addition to loneliness, this contributes to “political poverty”, meaning that members cannot participate in the public debate.

(4) Lack of communication with marginalised groups

It has proven to be difficult to bridge language barriers and reach out to groups who do not have Swedish as their mother tongue and who live in socially marginalised environments. There is a need for greater understanding of how different cultural and socio-economic backgrounds play a role in how to access and manage crisis information.

(5) Difficulties in reaching out to people with no access to digital media

As much of the crisis communication takes place via digital channels, it is difficult to maintain a dialogue with people without access to digital media, e.g. people with limited digital competencies and are not used to access digital media. This leads many to become dependent on second-hand sources from friends, relatives or caregivers who may themselves have difficulty relaying correct information.

(6) Insufficiently adapted messages

Non-local and non-individually adapted crisis communication may create disengagement among people and plant an inability to go from information to action since they do not recognize themselves in the national messages. The authorities’ crisis information is often shared on a national level and might not always apply on regional or local levels where the conditions differ.

(7) Lack of access to dialogue methods to create an understanding of the peoples’ various needs, situation, behaviours and conditions

There is a lack of methods and resources to create dialogue between authorities and different groups of people, such as people with disabilities, about their needs and how they want to be communicated with. How can, e.g. people with disabilities be involved in designing crisis communication that create conditions for them to take responsibility? To counteract “pandemic fatigue” and maintain behavioural changes, we need to understand more about how different people work and how to communicate with them in relevant ways.

These crisis communication challenges (1–7) are reframed as design opportunities:
How might we design methods, tools, or processes
1. for creating initiatives and knowledge among people with disabilities (and their caregivers) how to build crisis preparedness? (Challenge 1)
2. that create conditions for people with disabilities to access crisis communication on equal terms by bridging their lack of and/or inability to develop digital competencies? (Challenges 2, 5)
3. that invite people with limited digital competencies to participate in the public debate to counteract “political poverty”? (Challenges 2, 5)
4. that increase the awareness of the importance of building social crisis preparedness among people with disabilities? (Challenge 3)
5. that decrease loneliness and isolation during crises? (Challenge 3)
6. to reach out “beyond the words” when communicating with people from other cultures? (Challenge 4)
7. for hybrid crisis communication, oscillating between the digital and the analogue? (Challenge 5)
8. for creating individually and locally adapted crisis communication? (Challenge 6)
9. for involving different target groups in the development of crisis communication and technologies that engage? (Challenge 7)
10. for creating dialogue between the authorities and people with disabilities that increases authorities’ knowledge about and understanding of their needs, behaviour and life conditions during a crisis? (Challenges 1, 6, 7)

The methods, tools, processes referred to in the design opportunities might result in new solutions for crisis communication technologies or other relevant solutions that support people with disabilities in building crisis preparedness. In the next step of the co-design process, Develop, these design opportunities will be explored together with disability organisations. To not steer the creative process, we chose not to mention potential solutions in the formulations of the design opportunities.

Discussion

Based on the joint explorations involving both crisis communicators and disability organisations, seven crisis communication challenges were identified. A series of design opportunities were formulated pointing out directions of future development of enabling technologies targeting people with disabilities. The design opportunities open up for many possible solutions, but what form they will take is yet to be explored in the next phase of the co-design process, Develop. To ensure that people with disabilities are represented in all steps of the design process, also as creators of technologies, the co-design settings in the following phases should build on an innovative and inclusive approach that enable co-creation and participation on equal terms. To achieve this, people with disabilities should preferably be involved on a meta-level, that is, in co-designing the actual co-design setting and the design-oriented activities conducted.

The strategy used to get access to the experiences of people with disabilities was to go via the representatives of the disability organisations. Assuming such a strategy may bridge potential ethical and practical barriers for collaboration with this group. An important question to ask however, is to what extent the representatives are able to represent their members’ perspectives in this particular situation? Although the representatives have experience and are confident in their own role, they may have limited experience of partaking in joint explorations and research contexts. This uncertainty is important to acknowledge when validating the outcome of their contributions.

Due to the Covid-19 situation, all co-design activities were conducted in remote settings, which hold both potentials and limitations for how joint explorations can be organised to strengthen participation and democracy. Even if no physical meetings were possible during our study, we
could still arrange for representatives to directly contribute with a holistic perspective and their unique perspectives. However, social exchange and collaboration in remote settings also has its limits, which we experienced. Different levels of digital competencies reveal communicative inequalities and digital exclusion, which hinder exchange and equal participation in discussions and, e.g. when contributing with visual content in shared digital spaces. Using digital tools when collaborating in remote settings requires both knowledge, equipment but also abilities to handle and sort information. To create conditions for user participation in research on equal terms, require careful planning of the joint activities and that information is complete, clear and made accessible to the participants based on their individual abilities and competencies (Nolan et al., 2007).

Concluding remarks

The experiences gained from this research project show a need for improved dialogue methods to gain a better understanding of how to constructively communicate with people with disabilities and what supporting crisis communication technologies they would find useful. By creating conditions for dialogue between authorities and people with disabilities and the disability movement (Charlton, 1998), we may go beyond a normative view of what constitutes crisis communication and preparedness. In doing so, we also create conditions for learning from people with disabilities whose everyday lives have always been characterised by extraordinary circumstances, not only during times of crisis. Their lived experiences are a resource to learn from and something that could become an asset to improve crisis preparedness among all people.

This project represents a unique case and experiences, which means that the results to a limited extent can be generalised to the larger population (Denscombe, 2019). The work of developing solutions based on the design opportunities are also left to future research. More knowledge and awareness are needed about the importance of crisis communication technologies for disability organisations in a short- and long-term perspective. Further research should also carry out prospective studies on how people with various disabilities experience crisis communication in their everyday lives, particularly from an intersectional perspective.

Further on, not all disabilities are represented among the participants involved, in the, e.g. intellectual disabilities and multiple disabilities, which is a limitation in terms of the representation and inclusion (Miller and van Heumen, 2021). People with disabilities constitute a risk group, which implies that their participation must be handled with great caution and in particular during a pandemic. The possibilities for more extended participation in research are limited, for example, to invite participants as co-authors in articles and reports, which demands periods of intense contact and collaboration. These are questions concerning democracy and freedom of speech but also about capacity and capability during the Covid-19 pandemic. The participants contributing to this project have shown interest in continuing to engage in these issues.

References

Beauchamp, T.L. and Childress, J.F. (2013), Principles of Biomedical Ethics, 7th ed., Oxford University Press, New York, NY.

Charlton, J.I. (1998), Nothing About us Without us: Disability Oppression and Empowerment, University of California Press, cop, Berkeley.

Coombs, W.T. and Holladay, S.J. (Eds) (2012), The Handbook of Crisis Communication, Wiley-Blackwell, Chichester.

Denscombe, M. (2019), “Forskningshandboken. För småskaliga forskningsprojekt inom samhällsvetenskaperna (The Good Research Guide, for small-scale social research projects)”, Fjärde upplagan, Studentlitteratur, Lund.

Design council (2021), “The Double Diamond design process model”, available at: https://www.designcouncil.org.uk/news-opinion/what-framework-innovation-design-councils-evolved-double-diamond (accessed 12 May 2022).
Eriksson, M., Lundålv, J. and Nilsson, E.M. (2021), “Challenging norms of crisis preparedness by listening to voices from the disability movement in Sweden”, Proceedings of the International Crisis and Risk Communication Conference, Vol. 4, pp. 19-22, Orlando Fl: Nicholson School of Communication and Media, available at: https://doi.org/10.30658/ircc.2021.05 (accessed 15 January 2022).

Funktionsrätt Sverige [The Swedish Disability Rights Federation] (2017), “The Swedish disability rights federation”, available at: https://funktionsratt.se/om-funktionsratt-sverige-in-english/ (accessed 12 May 2022).

GDPR.EU (2021), “Complete guide to GDPR compliance”, available at: https://gdpr.eu (accessed 12 May 2022).

Interaction Design Foundation (IDF) (n.d), “How might we”, available at: https://www.interaction-design.org (accessed 12 May 2022).

Jackson, S.E., Joshi, A. and Erhard, N.L. (2003), “Recent research on team and organisational diversity: SWOT analysis and implications”, Journal of Management, Vol. 29 No. 6, pp. 801-830, doi: 10.1116/S0149-2063_03_00080-1.

Kilman, L., Andin, J., Hua, H. and Rönnberg, J. (red) (2021), Leva som andra. Ett biopsychosocialt perspektiv på funktionsnedsättning och funktionshinder (Live Like Others. A Biopsychosocial Perspective on Impairment and Disability), Studentlitteratur, Lund.

King, N., Horrocks, C. and Brooks, J. (2019), Interviews in Qualitative Research, Sage, Thousand Oaks, CA.

Lazarus, R.S. and Folkman, S. (1984), Stress, Appraisal and Coping, Springer, New York.

Lundålv, J., Nilsson, E.M. and Eriksson, M. (2021), “Norm-creative krisberedskap: Ett forskningsprojekt med syftet att utveckla metoder som stärker allmänhetens beredskap inför och hantering av samhällskriser såsom pandemier”, Rapport, RISE – Research Institutes of Sweden, Göteborgs universitet, Umeå universitet och Malmö universitet. (In Swedish).

Lundålv, J., Nilsson, E. and Eriksson, M. (2022), “Covid-19 pandemic coping strategies in a complex landscape of crisis communication: a participatory study with disability organisations in Sweden”, Baltic Screen Media Review (BSMR), Vol. 10 No. 1, pp. 141-161, doi: 10.2478/bsmr-2022-0010.

Lyngbäck, L.A., Bylund, C., Gillberg, C., Jones, G., Hultman, L., Larsdotter, M., Bahner, J. and Nelson, B. (2020), “The impact of COVID-19 on disabled citizens in Sweden”, iHuman, The University of Sheffield, available at: https://www.sheffield.ac.uk/ihuman/covid-19-blog/disability-and-covid-19-global-impacts/impact-covid-19-disabled-citizens-sweden (accessed 12 May 2022).

Miller, S.M. and van Heumen, L. (2021), “Inclusive online research with people labeled with intellectual and developmental disabilities during the COVID-19 pandemic: technological adaptations”, Journal of Enabling Technologies, Vol. 15 No. 2, pp. 122-135, available at: https://doi.org/10.1108/JET-12-2020-0051 (accessed 12 May 2022).

Nolan, N., Hanson, E., Grant, G. and Keady, J. (Eds) (2007), User Participation in Health and Social Care Research: Voices, Values and Evaluation, McGraw-Hill/Open University Press, Maidenhead.

Palen, L., Vieweg, S., Liu, S. and Hughes, A. (2014), “Crisis in a networked world: features of computer-mediated communication in the April 16, 2007, Virginia Teach Event”, Social Science Computer Review, Vol. 27 No. 4, pp. 467-480, doi: 10.1177/0894439309323202.

Priestley, M., Waddington, L. and Bessozi, C. (2010), “Towards an agenda for disability research in Europe: learning from disabled people’s organisations”, Disability & Society, Vol. 25 No. 6, pp. 731-746, doi: 10.1080/09687599.2010.505749.

RISE (n.d), “Norm-creative crisis preparedness”, available at: https://www.ri.se/en/what-we-do/projects/norm-creative-crisis-preparedness (accessed 12 May 2022).

Robson, C. (2011), Real World Research: A Resource for Users of Social Research Methods in Applied Settings, 3rd ed., John Wiley & Sons, Chichester.

Sanders, E.B.N. and Stappers, P.J. (2012), Convivial Toolbox: Generative Research for the Front End of Design, BIS, Amsterdam, NL.

Schön, D. (1984), The Reflective Practitioner: How Professionals Think in Action, Basic Books, New York.

Shakespeare, T., Watson, N., Brunner, R., Cullingworth, J., Hameed, S., Scherer, N., Pearson, C. and Reichenberger, V. (2022), “Disabled people in Britain and the impact of the COVID-19 pandemic”, Social Policy & Administration, Vol. 56 No. 1, pp. 103-117, doi: 10.1111/spol.12758.
Simonsen, J. and Robertson, T. (2013), *The Routledge Handbook of Participatory Design*, Routledge, New York, NY.

Swedish Research Council (2017), *Good Research Practice*, Swedish Research Council, Stockholm, available at: https://www.vr.se/download/18.5639980c162791bbfe697882/1555334908942/Good-Research-Practice_VR_2017.pdf (accessed 12 May 2022).

Tomlinson, B., Blevis, E., Nardi, B., Patterson, D.J., Silberman, S.M. and Pan, Y. (2013), “Collapse informatics and practice: theory, method and design”, *ACM Transactions on Computer-Human Interaction*, Vol. 20 No. 4, pp. 1-26, doi: 10.1145/2493431.

Trevithick, P. (2020), *Social Work Skills. A Practice Handbook*, Open University Press, Buchingham.

Further reading

Myndigheten för samhällsskydd och beredskap (MSB), [the Swedish Civil Contingencies Agency] (2022), “The Swedish civil Contingencies agency”, available at: https://www.msb.se/en/ (accessed 12 May 2022).

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