


Experiences of children with disabilities during the COVID-19 pandemic in Sweden: a qualitative interview study

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To cite: Fäldt AE, Klint F, Warner G, *et al.* Experiences of children with disabilities during the COVID-19 pandemic in Sweden: a qualitative interview study. *BMJ Paediatrics Open* 2022;**6**:e001398. doi:10.1136/bmjpo-2021-001398

Received 28 December 2021
Accepted 16 March 2022

ABSTRACT

Background The impact of the COVID-19 pandemic on people with disabilities has been described as a ‘triple jeopardy’. Not only have they experienced the negative social impacts of disease control measures, but access to required health services has been affected, and, not least, they are at increased risk of severe outcomes from COVID-19. This study aimed to determine how children with disabilities have experienced the pandemic in Sweden and its impact on their lives.

Methods Six children (5–13 years) were interviewed via video conferencing. An interview guide was adapted based on the children’s communicative abilities and included augmentative and alternative communication support. Reflective field notes were included in the analysis. The data were analysed using qualitative content analysis.

Results Two themes were identified: The child’s knowledge of Corona raises anxiety and fear; and Boring Corona makes the child even lonelier. The children had knowledge about and were worried about COVID-19, primarily about illness and death of their grandparents. The children longed for their grandparents and other social contacts at school, and life was described as boring and lonely. Many families lacked adequate tools to communicate with their children about the pandemic.

Conclusion Given adequate support, children with disabilities and communication difficulties can give insights to their unique life situations. The interviewed children reported significant impact on their life and school life. Children were worried about their grandparents based on their knowledge about the virus. The enthusiasm with which the children engaged in the interviews is testament to the need and right of all children, regardless of communicative competence, to voice their experiences

What is known about the subject?

- ▶ Children with disabilities have a right to form their views and express these freely, just like typically developing children.
- ▶ Children’s lives have been negatively affected by the COVID-19 pandemic.

What this study adds?

- ▶ Children with disabilities experienced loss of social contacts and felt bored and lonely during the pandemic.
- ▶ Children with disabilities shared the same worries about illness and death of their grandparents as shown in studies of typically developing children.
- ▶ Given adequate support, children with disabilities gave insights to their experiences—therefore, their communication and information needs should be considered in times of societal crises.



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INTRODUCTION

The impact of the COVID-19 pandemic on people with disabilities has been described as a ‘triple jeopardy’.¹ Not only have they experienced the negative social impacts of restrictions, but access to healthcare and rehabilitation services has been affected, and they are at risk of severe outcomes from COVID-19.^{1–3} The risk of COVID-19 among children with disabilities is presumed to be higher than among typically developing children.^{4 5} Negative impacts on health behaviours, such as diet and sleep patterns, and the mental

health of children with disabilities have also been described.^{6 7} A particular concern for children during the COVID-19 pandemic is the disruption to school attendance due to ‘lockdown’, which has been shown to have social and educational ramifications for children with disabilities.^{8 9} Swedish children could be an exception, as both preschools and lower-secondary schools have remained open throughout the pandemic. Sweden’s public health response to the COVID-19 pandemic has been held up as an international exception without enforced quarantines.^{10 11}

The United Nations Conventions on the Rights of the Child (UNCRC) describes children’s right to form their views and express these freely.¹² This also means involving children with disabilities in research, yet few studies do.^{13–15} Nevertheless, children with disabilities can give insights to their unique life situations¹⁶ and listening to their experiences would benefit their access to human rights. The challenges to include individuals with communication difficulties in research¹³

Table 1 Description of participating children

Disability as described by parent	Mode of primary communication during the interview
ASD	Speech directed to parent who mediated communication with the interviewer
Cerebral palsy	Communication board with bliss symbols, gross motor signals, vocalisation
ASD and intellectual disabilities	Speech and hand signs based on Swedish sign language
ASD and intellectual disabilities	Primarily speech
ADHD, hearing loss and developmental language disorder	Primarily speech
Degenerative muscle disorder	Hand signs based on Swedish sign language and vocalisation

ADHD, Attention Deficit Hyperactivity Disorder; ASD, Autism spectrum disorder.

can be overcome through use of graphic symbols, augmentative and alternative communication (AAC), and responsive interview guides adapted to the individual's needs.^{14 17 18}

METHODS

This study aimed to determine how children with disabilities have experienced the COVID-19 pandemic in Sweden and its impact on their lives. The study adopted an exploratory qualitative methodology, using semistructured interviews with children and reflective field notes from the interview, which were both analysed using qualitative content analysis.¹⁹

Participants

Inclusion criteria were that the child should receive interventions for a disability, and had been living in Sweden during 2020. Recruitment efforts intended to reach children with a variety of disabilities, gender and parent country of origin. The purpose of this was to create heterogeneity in experiences. Habilitation service units were asked to display study information and introduce the study to families. Study information was also disseminated on social media. Participating parents were asked if they knew other parents who could be interested in participating (snowball-sampling). No children were excluded.

Two girls and four boys, aged 5–13 years, participated in the study (table 1). All six children had communication difficulties. They lived in different parts of Sweden.

Data collection

A semistructured interview guide (figure 1) using pictorial support^{17 20} was developed based on a previous study in which the research group collected typically developing children's perceptions of the COVID-19 pandemic.²¹ Swedish children usually use the word 'Corona' when referring to COVID-19. Therefore, 'Corona' was used during the interviews and in this paper when a child's voice is expressed.

Before each interview, a member of the research team (FK and/or AEF) conducted an unstructured telephone conversation with a parent. The purpose of this was to inform methods to facilitate participation and communication, for example, specific symbols to use and sending

the interviewer's photo to one child. Materials for one child were adapted to the next child dynamically. For example, scales with numbers were created for one child with a mathematical special interest (see figure 2 for an example) and were thereafter used in the following interviews.

The interviewer (AEF) was a speech and language pathologist experienced in communication through AAC. She had no prior contact with the children or families.

All interviews started with open-ended questions, even when it was expressed that closed questions were typically used in communication. Open-ended questions were also used when probing (figure 1). Response options, using gestures and pictorial support, were provided for children who found answering open-ended questions difficult. The youngest child ended the interview prematurely; the remaining interviews covered the full interview guide. All interviews except one involved an adult who could act as an interpreter in communication breakdowns.

The interviews were conducted and recorded via a videoconferencing platform during December 2020 and January 2021. They lasted from 15 to 31 min (mean 21). Two types of data were collected: recorded interviews and reflective field notes, including the interviewer's

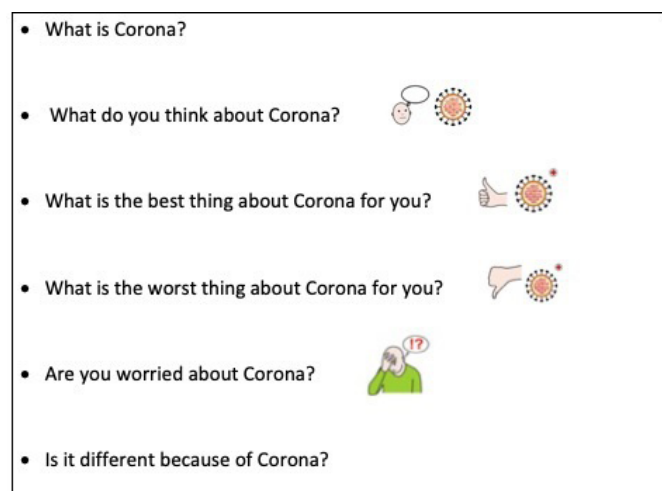


Figure 1 Interview guide with pictorial support translated to English. Symbols from Bildstod.se.



Figure 2 Pictorial support and response options used with a child with a mathematical interest translated to English. Symbol from Bildstod. se.

impression of the interview and the parent's comments before and after the interview.²²

Data analysis

The filmed interviews were transcribed and analysed inductively using qualitative content analysis.^{19–23} In addition, all the children's communicative signals were analysed, including spoken words, hand signs, pictures, body language and signs of increased or decreased tension. The approach placed equal weight on the children's statements, regardless of whether these were made with speech or AAC. Two children showed signs of echolalia. Only statements where echolalia could be reasonably excluded were coded as meaning units.

Data from the field notes were categorised deductively based on the categories that emerged in the analysis of the interviews. The field notes were used to validate and deepen the interview material and verify the analysis,²⁴ and are presented under each category. All parts of the analysis were a collaboration in the author group and were repeated until all authors agreed that the categories and themes correctly reflected the children's stories.

Prior to the interviews, study information was emailed to the children's custodians and written consent from the custodians were collected. The interviews began with the interviewer (AEF) introducing herself, informing that participation was voluntary, that it was recorded, and that the child could end the interview when the child so wished, whereafter the child was encouraged to show which signal it wanted to use to end the interview. Gender-neutral pseudonyms and 'their' as a gender-neutral pronoun are used in the presentation below to ensure protection of the children's identities.

Patient and public involvement

During the study's design, parents were engaged in the recruitment of participants and design of the interview guide.

RESULTS

Themes and categories are illustrated in [figure 3](#). The categories are presented with illustrative quotes from the interviews in [tables 2 and 3](#) and described in detail below.

According to the field notes, the children showed a strong commitment and willingness to voice their viewpoints regarding the COVID-19 pandemic. They also expressed joy and pride in contributing to research, and

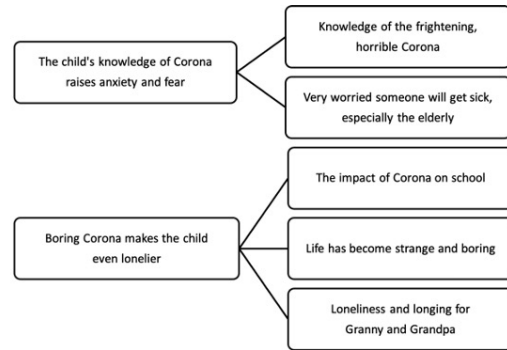


Figure 3 Overview of themes and categories.

the children's parents described them looking forward to participating. ('Sending a picture of Eli and the bliss board. Eli is so stoked about the interview' email correspondence with Eli's mother).

The child's knowledge of Corona raises concerns and fears

Knowledge of the frightening, horrible corona

All interviewed children showed recognition of the word 'Corona', some with emphasis. Many children explained what Corona is, and all children, except one, answered open-ended questions about COVID-19. The children's description of their own risks of becoming ill with COVID-19 varied. Most children were not worried about their own health, even though they were considered as a risk group for severe illness.

COVID-19 was described as frightening, with major negative consequences for people and the world. These were almost existential thoughts that aroused concern and fear. The children verbally described that COVID-19 is awful, and some rated it a clear nine on a 10-point 'awfulness scale'. The children spontaneously talked very little of benefits of COVID-19. On a direct question if COVID-19 was good for for example, nature on a scale of 1–10, some were able to mark their opinion.

Prior to the interviews, some parents expressed concerns that the child's participation in the interview would be limited. After the interviews, several parents described surprise over the child's high level of participation and communication. ('It was much better than I expected' Robin's mother).

Very worried someone will get sick, especially the elderly

The children described that they were worried someone will get sick and end up in hospital. Several of the children communicated that their anxiety mainly concerned the older generation. The concern for grandparents was recurring in several interviews. Parents who were present at the interview seemed surprised (inferred through facial expressions and intonation) that the children harboured such a concern.

Boring corona makes the child even lonelier

The impact of corona on school

The children described the influence of COVID-19 on the school or preschool. School has become more

Table 2 Theme The child's knowledge of Corona raises concerns and fears**Theme the child's knowledge of Corona raises concerns and fears**

Categories	Quotes
Knowledge of the frightening, horrible Corona	<p><i>Interviewer: "Kim, what do you think about Corona?"</i> <i>Kim: moves their tongue from the corners of their mouth at a high pace combined with large opening of their mouth and speaks fast with high intonation in their first language.</i> <i>The interviewer provides written support and hand gestures: "What do you think about Corona? Good, Bad, In between?"</i> <i>Kim: stills, says emphatically: "Bad!"</i> <i>The interviewer: "It is something bad"</i> <i>Kim: looks intently at the interviewer</i> <i>Interviewer: "How worried are you that you might get sick then? One is not worried"</i> <i>Eli: nods</i> <i>The interviewer: "The second is a little worried"</i> <i>Eli: gives a big repeated nod and waves their hand</i> <i>The interviewer: "Itsy-bitsy-tiny-winy worried that you will get sick yourself?"</i> <i>Eli: gives a big nod and makes a confirming sound</i></p> <p><i>Interviewer: "Is there anything else you are worried about?"</i> <i>Michele: "Anything else. That maybe it's the end of the world or if it starts to get more dangerous, or if like maybe everything is shut down. And it will all end, like now, this second"</i> <i>The interviewer: "Sounds pretty scary, to think about"</i> <i>Michele: "That is, everything is shut down and everyone dies. I'm scared shitless about that"</i> <i>Robin: "Everything is awful", signs the hand sign for terrible</i></p>
Very worried someone will get sick, especially the elderly	<p><i>The interviewer: "Those who are old would get sick, how worried are you about that then? (starts moving the pointer along a scale). Not worried at all, tiny little worried a two, a three... a little worried, now we are on worried now here more than worried"</i> <i>Eli: nods</i> <i>Interviewer: "Is it okay at six?"</i> <i>Eli: stops nodding</i> <i>Assistant: "More worried"</i> <i>Interviewer: "Even more worried? Up here then on really really really worried, super worried? A ten?"</i> <i>Assistant: "Are you really worried? Do you want to show a lot or a really?"</i> <i>Eli: shows a gross motor signal interpreted as a lot and really</i> <i>The assistant: "Yes then it's so, then it's like ten, when Eli does that"</i> <i>Interviewer: "Are we up to ten? Was it okay with a ten? Is ten good?"</i> <i>Eli: nods</i> <i>The interviewer: "A ten is, really really, very-mega worried"</i> <i>Eli: nods big, sits still and points to the communication board</i> <i>The assistant: "Mm, thinking of grandma to die, grandma and eh... Grandpa, they are special. Anyone else?"</i> <i>Eli: shows signs of no</i> <i>The parent: "Who are you afraid of ending up in the hospital?"</i> <i>Bobbie: makes a hand sign (not known to the interviewer)</i> <i>Parent: "Grandpa? ... But you said you were afraid that someone would end up in the hospital there, is there anyone in particular you are worried about?"</i> <i>Bobbie: signs hand sign</i> <i>Parent: "Grandpa? Oh, ok..."</i></p>

boring, for example, in those external visitors, including parents, could not visit/be there. Others described and showed discomfort when they talked about crowding at school and that other children did not follow the guidelines. The anxiety about being in school varied, one child showed intense anxiety while another thought the discomfort corresponded to three on a 10-point scale. The children said they had been more absent

from school than usual. One child had been absent from preschool from the start of the pandemic, and described longing for school and friends.

Life has become strange and boring

The children described that it is boring and strange with COVID-19, that activities they like have been cancelled. Throughout, the children described how bored they felt,

Table 3 Theme boring corona makes the child even lonelier

Theme boring corona makes the child even lonelier

Categories	Quotes
The Impact of Corona on School	<p>Interviewer: "What do you think about school now with Corona?"</p> <p>Michele: "Yes, I think many people are pretty close to each other, mostly in like the dining hall and then like when you stand in line so like everyone is pushing their arms against each other(...)And in the corridors, it's the same, there are many people."</p> <p>Interviewer: "Here we are at one, it is as usually, you get to be with your friends, the ones you usually hang with?"</p> <p>Eli: looks away</p> <p>Interviewer: "No(...)here four, in between, a little different"</p> <p>Eli: looks away</p> <p>Interviewer: "No, six, you feel a little lonely... quite lonely, now we are up alone. And up here we are on super-duper very lonely"</p> <p>Eli: tilts head back, looks up, nods big</p> <p>Interviewer: "Yep, you feel like you've become more lonely when it's Corona, okay"</p> <p>The parent: "So then she asks like this, what is it like not to be in preschool? Do you think it's fun to be home so much, do you think it's boring not to be in preschool?"</p> <p>Bobbie: "aah!"</p> <p>Parent: "Boring"</p>
Life has become strange and boring	<p>Interviewer: "And has it made life more boring for you, or how has it affected you?"</p> <p>Michele: "Ah I liked being at the community pool the most...(..)cinema too, ah yes! So, it's like, I think cinema is the nicest, best of all(..)I miss a lot of things!"</p> <p>Alexis: points to the screen</p> <p>The parent: "Which one did you point to?"</p> <p>Alexis: points again "Boring"</p> <p>Parent: "Boring"</p> <p>Interviewer: "Boring, yes, you know, I also think it's very, very boring with Corona, super boring(...)But how boring is it then with Corona? Not boring, or in between, whatever number you want or super-duper boring on ten"</p> <p>Alexis: "Seven!"</p> <p>Robin: points at the screen "look, I, alone"</p> <p>Interviewer: hand signs the sign alone, "you feel, then you feel alone?"</p> <p>Robin: signs feel "ah, I feel, alone"</p> <p>Michele: "So I mean it gets worse and yes many get even lonelier."</p> <p>Interviewer: "It's not like you're lonely, but you think of everyone who's lonely?"</p> <p>Michele: "No I do not feel like, really alone"</p>
Loneliness and Longing for Granny and Grandpa	<p>The interviewer: "But who are you missing then? Is it, maybe it's "grandfather" signs the hand sign for elderly man, "or grandmother or some friend, who are you missing?"</p> <p>Robin: signs the hand sign for friend</p> <p>The interviewer: "Friend, are those the friends you are not allowed to be with?"</p> <p>Robin: "Friend, grandma, grandpa, grandmother, grandfather*"</p> <p>Interviewer: "But who do you miss the most?"</p> <p>Robin: signs an unrecognized sign interpreted as a name</p> <p>Parent: "Grandma"</p> <p>The interviewer: "Yes, you feel that you have become more lonely when it's Corona, okay... who are you missing, who are you not allowed to meet?"</p> <p>Eli: looks down at the communication board, and points repeatedly</p> <p>The assistant interprets the child: "... Grandma, Grandpa, the whole gang"</p> <p>Interviewer: "Yes, I see that you point super much at Granny now"</p>

*In Swedish, the word for grandmother and grandfather alters if it is the mother's or father's parents.



even children who could not describe what they were missing.

Loneliness and longing for granny and grandpa

Several children said they felt lonely, 10 on a 10-point scale, which was expressed with emphasis by children talking and signing. Some also described a concern for the loneliness of others. Almost all children described that they longed for their grandparents.

DISCUSSION

With adequate adjustments all children could participate in the interviews and describe their experiences. The children showed great commitment and, according to the parents, had looked forward to the interviews. This was interpreted as the children's wish to narrate their experiences, which has been found in previous research with the target group.²⁵ Parents voiced surprise over the child's level and quality of participation in the interviews, a signal of low expectations on the child's communicative abilities. These low expectations can serve as a barrier for children to voice their opinion and experiences.²⁶ All children used the pictorial support offered through the interview guide. Pictorial support has in previous studies helped children to maintain concentration²⁰ and enabled participation.²⁵ This shows the importance of offering adequate conditions for children to express their opinions, fully in line with the UNCRC's freedom to express oneself.¹²

The children's narratives are similar to previous results with typically developing children who described knowing and worrying about COVID-19 and fearing illness and death in the older generation.²¹ However, children with disabilities often have smaller social networks,^{27 28} and the absence of grandparents may be more pronounced and have a greater impact on the child's life compared with typically developing children. Accordingly, the children described that life was more boring during the COVID-19 pandemic and feelings of loneliness were extremely pronounced.

Despite explicit governmental COVID-19 policies to keep schools open in Sweden,¹⁰ the children in this study reported an impact of the pandemic on their school life. Some were prevented from attending school due to infection risk. The absence of peer interaction is likely to have had adverse effects on the children.²⁹ Even for those attending school, school routines were affected by pandemic-related restrictions, limiting fun activities and changing mealtime routines. Furthermore, professionals and parents who otherwise routinely participate in the child's schooling were not allowed on the premises. Interactions with adults at school is more important for children with disabilities³⁰ and previous international research indicates that parent involvement is crucial for the academic success of students with disabilities.^{31–33} Thus, access restrictions and changes in school routine might have affected this population especially negatively.

A pronounced difference between our previous study²¹ and this study is that children with disabilities saw very few, if any, benefits of the pandemic. In the previous study, children described more time with the family, less school stress, and positive effects on climate and nature.²¹ One explanation could be that the disadvantages of the pandemic outweigh any potential benefits for children with disabilities and their families.

Methodological considerations

The recruitment of children aimed at heterogeneity of relevant backgrounds, such as disability, age and gender to include different experiences. Although the sample was fairly heterogeneous, transferability might be affected by the children's interest in and awareness of the topic. On the other hand, the results align with our previous study with typically developing children which increase the reliability of the result.²¹ The credibility was addressed through careful construction of the interview guide and ensuring that all aspects were covered with all children. The field notes added trustworthiness to the findings.³⁴ Dependability was ensured through multiple coders and repeated consensus meetings among the authors.

The interviewer, experienced in communication through AAC, initially perceived interviews through videoconferencing as complex. However, videoconferencing allowed the children to participate while being at home.

To ensure the findings were based on the child's own experiences, statements that may have been echolalia were not coded as meaningful units for two children. To minimise the risk of neglecting these children's opinions,³⁵ body language and intonation signalling engagement were analysed as described in Dindar *et al.*³⁶

Interviewing children with limited speech is a challenge. Communication is a continuous and co-constructed process between the communication partners.^{37 38} In a conversation using AAC, the communication partners often use a great variety of communication modes, such as speech, gestures, facial expressions, graphic symbols and hand signs.¹³ This dynamic process can potentially risk leading the child and affect their responses. To strengthen the interpretation of the interview, such as how the grading questions were being used by the children, topics unrelated to the pandemic could have been incorporated. All communication modes were also used in the analysis which poses certain risks, something which might amplify the element of interpretation. There are, however, methods to analyse non-verbal communication modes,³⁹ which we used when further analysing three of the interviews, confirming of the themes described in this paper.⁴⁰

CONCLUSIONS

This study explored how children with disabilities have experienced the COVID-19 pandemic in Sweden and its impact on their lives. The children's stories were

in line with typically developing children in many ways. The interviewed children had knowledge about and were worried about COVID-19. The concern was primarily about illness and death in their grandparents. The children also missed their grandparents, and life was described as boring and lonely. Despite governmental COVID-19 policies to keep schools open in Sweden, the children in this study reported an impact of the pandemic on their school life. The unselective banning of all 'visitors' from schools resulted in missed educational opportunities and lack of support in school routines for several of these children, who were otherwise able to attend schools.

The study demonstrates that children with disabilities can give insights to their unique life situations. The enthusiasm with which the children engaged in the interviews is testament to the need and right of all children, regardless of communicative competence, to voice their experiences of disruptions in society. It is up to us as professionals to facilitate these discussions, for example, by providing families with pictorial support or adapting children's AAC systems and thus assuming children's interest and competence to discuss matters concerning them. Further research conducted directly with children with disabilities recognising them as individuals who have their own agency and epistemic contribution is encouraged to explore the need for compensatory mechanisms needed after the pandemic regarding educational and social needs.

Acknowledgements The research team would like to acknowledge the children and parents who took part in the research.

Contributors AS initiated, conceptualised and was PI for this study. GW contributed to the study design, including the interview guide and data collection methods. FK and AEF collected data. AEF and FK designed and performed the initial analysis, which was discussed with AS and GW. All authors contributed to data interpretation, and AEF, AS and GW wrote the manuscript. All authors had input to the manuscript and have approved the final version. AEF and AS guarantors for the study content.

Funding The work was supported by the Swedish National Agency of Public Health (Grant # 03303-2020-2.3.2).

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval The study was approved by the Swedish Ethical Review Authority Dnr 2020-05096.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement No data are available.

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