

Disabled children's, young people's, and carers' experiences of accessing healthcare services and supports during the pandemic: a qualitative research report



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Summary of methodology and findings

The study

Drawing on children's, young people's and parents' own accounts, this study explores the impacts of the pandemic on access to health care, social care services, state entitlements and supports in Scotland. Five families with children and young people living with different types of long term conditions, or experiencing particular care needs, were interviewed over three online sessions between March and May 2022. Interviews were supported by creative and digital tools, such as visual prompts, body maps,¹ and/or Miro² sticky notes. Children and young people decided the times and dates of the online sessions, as well as whether their parents would be present during the interviews.

Main findings

- **Participants reported sudden closures of health services, which included primary, secondary, and tertiary care. There was a consensus among the participants that they did not receive a formal notice/letter informing them of healthcare services closures, or instructions on what they should do to have their appointments or regular treatments in place. Not having 'communication lines open', particularly with healthcare services, made participants feel abandoned, with their complex healthcare needs unmet.**
- **Health services closures had negative impacts on children's and young people's symptoms and progression of their health conditions. Poor control of symptoms, such as chronic pain, mobility difficulties, and mental health issues, affected their everyday lives in stringent ways.**
- **There were mixed opinions about digital health and care options among children, young people, and their parents. For some children, online appointments with consultants implied less time traveling and associated costs, something that was perceived as positive. However, for other participants, online occupational and physical therapies were found less interactive and engaging.**

1 This creative tool aims to explore how children feel about their bodies. It consists of a drawing of a body (girl and boy) with empty boxes on different body parts and segments (e.g. head, legs, hands). Children are encouraged to select an emoji (from the emoji pad) that reflects their feeling with a particular part/segment of their bodies and stick it on the empty box.

2 Miro is an online whiteboard platform which allows people to work together on projects, ideas, proposals. Different tools can be used such as digital sticky notes, mind maps, diagrams, workflows.

- **Social isolation and mobility restrictions related to lockdowns had negative impacts on children's, young people's, and carers' mental health. Participants linked these to the limitations on everyday life that they experienced, caused by the poor control of children's and young people's conditions and concerns about their present and future lives.**
- **Access to mental health support was perceived by children, young people, and parents as extremely limited. Long waiting lists, short encounters with therapists, and sessions where children and young people felt that their concerns were not heard, were some of the barriers they listed.**
- **Access to medications was not significantly disrupted by the pandemic, with only some delivery delays and medications being out of stock. Some participants associated these delays to political circumstances, such as Brexit, rather than the pandemic.**
- **Participants felt that decisions about healthcare closures and pandemic-related protocols, such as non-resuscitation notices, were not properly contextualised and poorly thought out. There was a general feeling that applying blanket statements and policies was the norm during the pandemic, revealing that people's particularities and own opinions were not considered by decision makers.**
- **The social care and social security systems were a distant and unfamiliar topic for the children and young people interviewed; the process of applying for and claiming benefits was mainly in the hands of their parents. Children's and young people's limited knowledge about the benefits and supports they were entitled to was linked to the complexity of these topics.**
- **Parents shared that what they knew about the supports their children could access they found out through informal conversations with friends, school teachers, neighbours, and (less frequently) through social workers.**
- **Families had access to a range of state benefits and supports, which mainly helped them afford services such as personal assistants, care workers, transportation, and housing. Parents also drew on other financial sources (charity support, fundraising events, their own income) to meet their children's care needs.**
- **In relation to carers' benefits, access to carers' allowance was limited by parents' migration and work status. Those working full time, with wages over certain amount of money per week, and without settled or citizenship status, were not eligible for this financial support, despite being the primary carers for their children.**
- **The process of applying for benefits and being assessed was described by parents as a 'nightmare'. Apart from long turnaround times, parents also found terminology and the language on forms complex and repetitive. Furthermore, general information about benefits, eligibility criteria, and the process of assessment available on the Scottish Government website was made only available as text. No alternative formats (e.g. Audio versions, videos, closed captions, BSL/English interpretation) or information in other languages were available.**

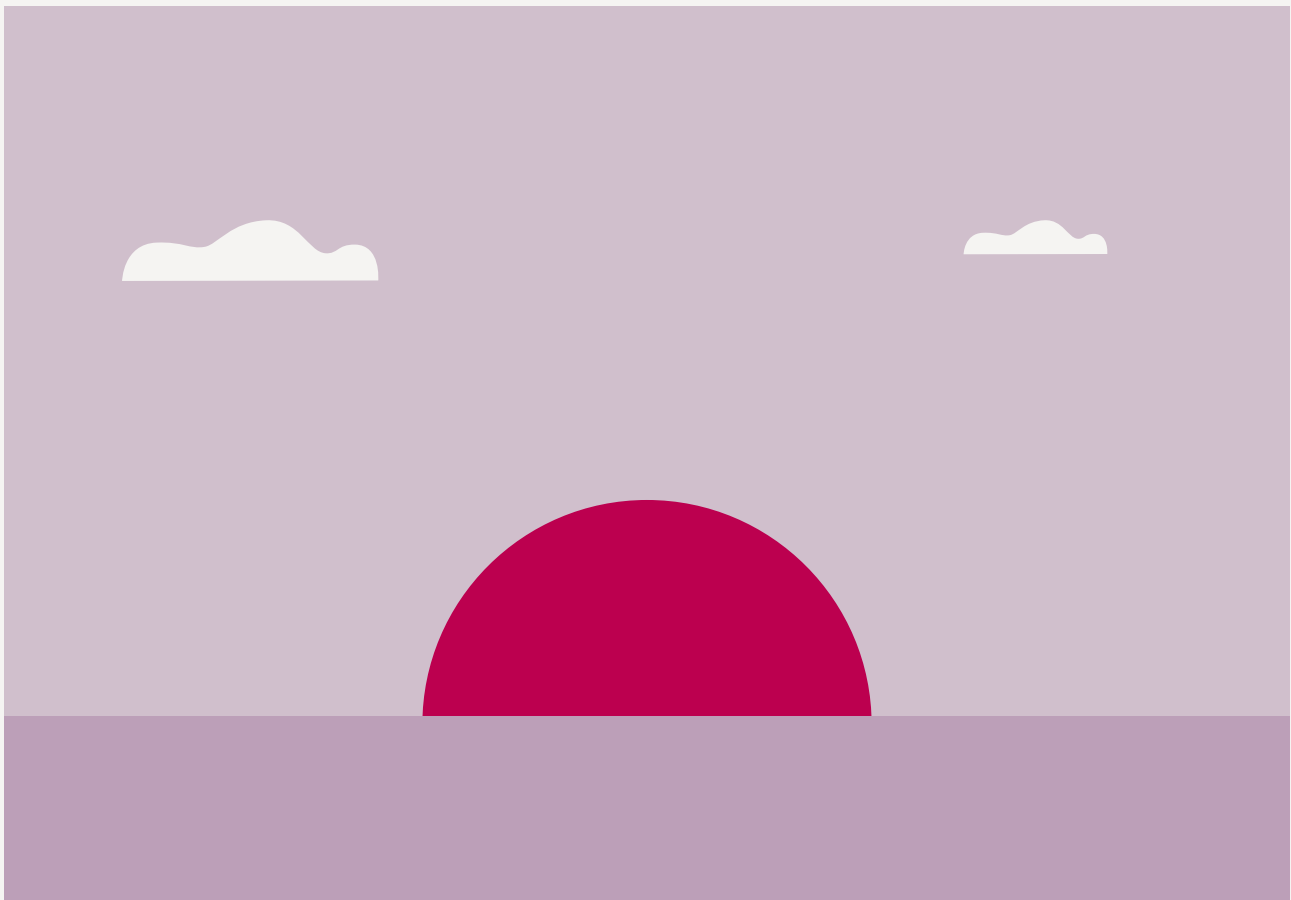
- **Parents valued the financial support received through allowance and payments, but also felt that they and their children needed other types of support. In particular, they wished they had ‘someone in the system’ with whom they could share their concerns, struggles, and with whom to sense-check decisions about their children’s care, particularly during difficult times.**
- **The general perception of those parents who had sporadic contact with social workers was that they were very creative and supportive agents. Parents especially valued the presence of a social worker with a holistic view of their and their children’s ‘situation’; those who did not only look at the government benefits, eligibility criteria or their children’s medical condition, but who understood the unique particularities of their lives and contexts.**
- **In some instances, parents explained they had to demonstrate their children’s disability status through medical certificates and notes to get access to care centres. This is reflective of an approach to disability still dominated by a medical model in practice. Narratives about assessment processes also reflected a mainly medical approach and/or understanding of disability. Questions during these processes tended to be focused on evaluating changes of children’s medical conditions instead of looking at other dimensions of their experiences. For instance, questions such as how included in society did children and young people feel, or whether different environments and social structures meet their needs, were omitted.**



Introduction

This report brings together the methodological aspects and findings of a qualitative research project conducted between March and May 2022 with a group of disabled children, young people, and their parents in Scotland. Drawing on their own perspectives and experiences, this study provides insights into the impacts of the pandemic on their access to healthcare, social care, and other supports. This study also draws out additional findings, such as the limited understanding and engagement of children and young people with the social care and social security systems. The child-centred nature of this study responds to the need to listen to, and better understand, disabled children's and young people's own views and experiences, and their proposals for future change.

This report is structured in four sections. The first section provides some context and background to the research. It also presents the aims and research questions of the study. The second part (methodology) offers a detailed description of how the research was designed and conducted, also providing participants' profiles.³ This is followed by the presentation and discussion of the main findings, which are organised in two main subsections: 1) experiences with health services, and 2) experiences with accessing state entitlements and supports. The report ends by outlining some of the recommendations proposed by the participants, and potential avenues for future research.



³ All participants' names have been changed to ensure anonymity.

Background and context

Part of the strategies to mitigate the COVID-19 pandemic in Scotland was the implementation of strict controls and restrictions on movement. Although these measures were important to reduce transmission rates and to prevent a collapse of healthcare services, they also caused significant challenges for both individuals and communities. Lockdowns brought about social isolation, mobility restrictions, school and health services closures, reductions to social care support, among other situations, which affected those who are most likely to rely on these services in more stringent ways.

The impacts of the lockdowns and the pandemic on people's health and wellbeing have been extensively documented. For example, drawing on interviews with communities across the UK, *living through a pandemic* (mchardy et al., 2021) documents how families on low incomes have faced extra challenges when accessing food, IT connectivity, and costing basic needs during the pandemic. Apart from financial pressures, parents have struggled to balance their caring roles, home schooling, and work, leading to negative impacts on their work productivity and mental health (mchardy et al., 2021; Patrick et al., 2022; Scottish Government, 2021).

The experiences of families where at least one person has additional support needs have been also explored. Both *the experiences of vulnerable children, young people, and parents during the Covid-19* report (Scottish Government, 2021) and a large consultation with children and young people with special educational needs in England (Kaisen Partnership & The Council for Disabled Children, 2021) highlight how disabled people and those with special education needs were faced with a lack of support, with access to primary care services being particularly affected.

Lockdowns and the pandemic also uncovered a very fragmented public service landscape. Informed by the everyday experiences of families with children on low incomes during the pandemic, the *Covid Realities research programme* (Patrick et al., 2022) reveals a social security system failing to provide people timely and appropriate social support. In the same vein, *My Support My Choice: People's Experiences of Self-directed Support and Social Care in Scotland - National Report* (The Health and Social Care Alliance Scotland (the ALLIANCE) and Self Directed Support Scotland, 2020) raises questions about the extent to which information about the social care is presented in accessible formats, and whether decision making processes about self-directed support is sufficiently informed and accompanied by social workers.

Although these works offer valuable and in-depth insights into people's lived experiences during the pandemic, and highlight concerning areas in health and social care and social security these studies have been conducted mainly with adults. This is problematic as children and young people, particularly those with long term conditions, additional support needs, or who are disabled, may be additionally impacted by changes in schooling, healthcare services, and other supports. Further, disabled children's and young people's views remain overlooked, thus making listening to their views something particularly urgent to address. This study addresses this research gap.

Aim

To explore disabled children's, young people's, and carers' experiences of accessing state entitlements, including healthcare services, social care, and other benefits, in Scotland during the COVID-19 pandemic.

Research questions

- **What state entitlements and supports have disabled children, young people and their families been able to access during the pandemic? E.g. Healthcare (including mental health), allied health services (physiotherapy, speech and language), social care (including day centres, short breaks, access to food), state benefits (child payment, disability allowance, carer allowance, etc).**
- **What do children and young people think has changed about their care and support during the pandemic?**
- **What do children, young people and their carers think of the quality and accessibility of the services and supports they have access to?**
- **How do children, young people and carers know about the benefits and supports they can have access to?**
- **What are the key priorities for children, young people, and their families going forward when accessing health and social care services, support, and benefits?**
- **What would children, young people and their carers like to see change about their experiences with health and social care services, support, and benefits?**



Methodology

Design and ethical considerations

Given that disabled children's and young people's voices are often left unheard or are accessed by proxy (Kaisen partnership & The Council for Disabled Children, 2021), we wanted to adopt a methodological approach that foregrounded children's and young people's own accounts. Reflecting this, online qualitative interviews with a participatory component was considered an appropriate approach to explore children's and young people's views and experiences.

We designed an online interview structure that encouraged children, young people, and their parents to speak of their experiences in ways that were most convenient and comfortable to them, at times and dates that suited them. The decision to conduct online interviews was taken for safety and ethical reasons. Face-to-face interviews might increase the risk of COVID-19 infection for both participants and the researcher, something that in the case of children and young people with complex health conditions might represent higher health risks. We also adopted the Scottish Government's recommendation to maintain physical distance and to limit face-to-face encounters.

Although online/remote methods have proved to be effective in cases of mobility restrictions such as lockdowns, we were also aware of their limitations. These include more difficulties to build rapport with participants, potential technology issues, and poor connectivity, all factors that might have negative impacts on the data generation. Relying on online methods for both recruitment and interviewing also meant that those families without access to IT equipment or connectivity might have had less opportunity to hear about the research and participate.

These limitations were partially addressed through the following strategies:

- 1 We opted for an online approach based on three separate sessions or encounters. Multiple encounters meant greater interaction between participants and the researcher, with more opportunities to construct relationships of trust, and to carry out a deeper exploration of participants' experiences and views.
- 2 To minimise technology issues, we ensured a high speed Wi-Fi on the researcher's side.
- 3 We implemented offline recruitment strategies, such as handing out flyers in selected locations (in Edinburgh), such as outside schools, inside care centres and cafes, to reach potential participants with no access to internet.

The study is theoretically informed by the new paradigm of childhood (Corsaro, 2018; Qvortrup et al., 2009), which promotes a vision of children and young people as active members of society, and rights holders. In line with this, we recognise that children are able to talk about their lives, and topics that matter to them, on their own. This project is also informed by the social and rights based models of disability. Both models look at disability beyond the presence of a medical condition, biological vulnerability, or bodily impairment. According to these models, disability is generated and/or exacerbated by non-inclusive social structures that limit disabled people's participation in society (Degener, 2016; Lawson & Beckett, 2021). Following these models, a medical diagnosis of disability was not considered in the eligibility criteria for participant recruitment. Instead, we wanted to involve participants who self-identified as being disabled, or with special care needs, regardless of their diagnosis and condition.

We aimed to recruit a small sample, to generate and analyse in-depth qualitative data within the timescale of the research. This also reflects the qualitative nature of this study, which did not seek to ensure epidemiological representativeness (Barbour, 2001). Instead, we wanted to generate in-depth insights about participants' experiences and social world phenomena by drawing on people's views and stories.

Consent, confidentiality, anonymity

This study was designed and conducted following the Third Sector Research Forum's 'Guide to Applying Ethical Research Principles' (Scotland's Third Sector Research Forum, 2020). We are also aware that a key aspect of doing research, particularly with children, is seeking consent, which should be an ongoing process. For that reason, consent was sought at different points of the research. This started by checking children, young people and parents' agreement to participate at the end of an initial chat with the researcher. This often took the form of an informal discussion over whatsapp, email, or phone with families interested in knowing more about the study and potentially taking part. During these conversations, the researcher explained the aims and nature of the project, and parents and children also asked questions. This encounter was particularly important to get to know the researcher, something valuable for building rapport and trust.

Two different consents forms were designed, one for children/young people and one for parents. In the first section of the children's and young people's consent form, their understanding of the voluntary nature of the study, the confidentiality of their accounts, and limitations of this confidentiality in cases of risks and potential harm, was checked. Children's and young people's agreement to participate was checked in the second part of the form. Consent forms for children and parents were emailed to parents, who returned the forms completed and signed. Verbal consent was gained from all children and young people in the first interview.

In the first interview, after a brief recap of the aims and voluntary nature of the study, verbal consent was also gained from the children, young people, and their parents. At this point, children also decided whether they wanted their parents to be present in the following two interviews or not, this to further ensure the confidentiality of their accounts, and offer a research context consistent with their preferences. Participants were reminded about the voluntary nature of their participation, their right to skip any questions, and to drop out from the study throughout the interviews.

It is important to mention that consent was not sought from one young person (referred to as Bob in this report). He was also not interviewed, due to his complex health condition and communication, which was mainly 'receptive', in his mum's words. While some visual prompts and communication tools such as 'Talking Mats' can be helpful in these contexts, particularly with young people used to using visual based communication tools, this was not the case for Bob. However, we wanted to listen to his mum's views and experiences who, as the main carer, were equality important to capture. Although the accounts of Bob's mum are not intended to be reflective of Bob's own personal experience, her stories provide important insights into the complexities of meeting Bob's care needs during the pandemic.

A data management plan (DMP) was designed early on the research process. This covered the capture, storage, confidentiality, retention, destruction, and sharing of research data. Personal data such as names, contact details were solely accessed by the researcher, and not included in the transcripts. A pseudonym for each participant was selected as unique identifier for their transcripts and audio recordings. When discussing data with the ALLIANCE, access to selected documents were granted via a file hosting service (onedrive). Specific details of participants' medical diagnosis that might reveal their identities are not included in this report.



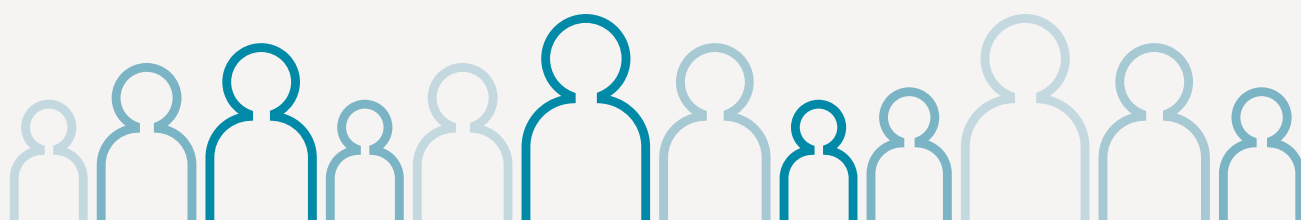
Inviting children, young people, and parents to participate

A call for participation with key information about the research was disseminated through the ALLIANCE website, their social media, and key partners. This call included two types of information sheets, one for parents, and one for children and young people. An audio version of both information sheets was also accessible through a QR code. The website link to the call for participation and a flyer were also circulated through several professional networks, friends, and colleagues to maximise the potential for involvement.

This stage of the study was particularly challenging, as uptake was significantly slow. Following two weeks of the initial call, only one family had made contact, leading us to think of alternative solutions. Various third sector organisations, sport and dance centres, wellbeing hubs, and one school in Edinburgh were contacted to assist in disseminating the study. Some of these organisations sent targeted messages to key people and teams working with disabled children and young people and advertised the study through their own channels. This outreach was supported by in-person visits to schools and centres in cases when making contact by email was not successful. Flyers were also left at some care centres, and handed in to parents and people on the street. The study was also advertised in the showroom of the wellbeing and disability centre at the University of Edinburgh.

The participants

Five families took part in the study with children and young people's ages ranging from nine to 19 years. All participants self-identified as living with a long term medical condition, or caring for a disabled child or young person. Children and young people experienced varying degrees of mobility, cognitive, and communication difficulties, mental health issues, and/or everyday symptoms, such as pain and fatigue, which affected their lives and their families in different ways. In the majority of cases, children and young people's medical conditions associated to their experiences of disability were present since birth or early on in their lives. There was only one participant whose experience of disability was associated to Long Covid, a condition recently diagnosed. Of the children, young people, and carers who took part, three were female and two male. Two of the participants turned 18 during the pandemic. Families were located in urban and rural areas of Scotland, and spread across the North, South, and Central Belt. Given the individual focus of this research, a particular section is provided below to let readers know more about our participants' personality, preferences, routines, symptoms, and future plans. This is provided to offer a more contextualised and individualised picture of the data.



Case 1: Kristi

Kristi is a Scottish 18-year-old young woman, who loves animals and the countryside. She lives with her parents, and has an older brother who does not live at home. She enjoys doing a range of sports and music activities and is also involved in some activism. She turned 18 during the pandemic, something that has made her transition process to adulthood challenging. For example, she felt that there was no time for a proper transition, as she had to make a decision about starting college very quickly. She is now also out of the children's healthcare system and has not transitioned to the adult one yet. She is attending college, where she is learning and developing skills for an independent life.

Kristi was born with a genetic/congenital condition that has required both medical and surgical care. She has some mobility requirements, dental, eye, and neurological symptoms that need to be monitored and followed regularly. Her main consultants include an ophthalmologist and a neurologist, the latter of whom is not based in Scotland. Kristi hopes to have a more independent life and to get a job in the future. She would like to work with animals or looking after other people's pets.

Case 2: Matt and Lisa (Matt's Mum)

Matt is a Scottish 13-year-old young person. He loves playing video games, such as Xbox, and wheelchair football. He also likes history and social sciences, which is his favourite subject. He lives at home with his parents and two siblings: one younger and one older. In his words, they 'enjoy annoying each other'. He attends school, which is five minutes away from home. Over the weekend he often visits his grandparents, plays wheelchair football, or stays at home.

Matt was diagnosed with spastic quadriplegia, secondary to cerebral palsy. This is the reason why he requires some mobility assistance, and close medical follow-up and control of his condition is a priority, particularly of his legs' muscular tone which causes severe pain. Before the pandemic, he would have Botox injections twice a year to control his muscles and associated pain. However, it has been more than two years since he received his last injection, which has made his symptoms worse.

Case 3: Emma and Kati (Emma's mum)

Emma is a nine-years-old girl. She lives with her mum and does not have any siblings, instead she has three cats. She contracted COVID-19 twice over the last two years and now she is struggling with very complex symptoms associated to Long Covid. Her everyday life is currently extremely limited by fatigue, issues with her sense of smell, mood swings, sleep troubles, anxiety, and difficulties concentrating. Before getting sick she used to enjoy horse riding and swimming.

She is now at home with her mum most of the time. Emma likes online gaming, and plays the piano. They also watch movies together and, depending on Emma's symptoms, also do some outdoor activities, such as going to the beach and visiting a farm. Emma would like to learn how to create her own online games in the future.

She has not been able to attend school for two years as a result of her complex and recurrent symptoms. She gets tired easily on the computer, which makes her engagement with online school very challenging.

Emma's dad does not live with her and comes to visit her once a month. Kati, her mum, is responsible for Emma's care 24/7, and does this alone, as currently she does not have family support. Kati works part time and combines her work duties with her very challenging caring roles. She felt exhausted and deeply disappointed about not having the support they need from the health and social care system.

Case 4: Bob and Andrea (Bob's mum)

Bob is 19 years old. He and his family moved to Scotland from overseas some months before the pandemic started. He has a younger sister and until very recently he lived at home with his family. He now lives on his own near his parents' home. He has a diagnosis of a complex and uncommon genetic condition. As a result, since very early in his life, he experiences different types of seizures, which have negatively impacted his neurological system. He needs full support to carry out all basic everyday activities, such as personal hygiene, mobility, and eating. His communication is mainly 'receptive'⁴ and he has no sphincter control.

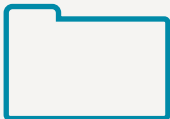
4 Andrea (Bob's mum) explains that communication with his son is mainly receptive. This refers to the process of receiving and understanding a message from another person. In the case of Bob, it is the ability of the other to understand Bob's needs and feelings without the use of verbal language.

He also needs special healthcare support, including a vascular access point⁵ (VAP), which needs to be monitored and cleared regularly. This is important to secure a vascular access, particularly in emergency cases. He receives his nutrition through a feeding tube. He also has a small device implanted under his skin called VNS (vagus nerve stimulation) to help control the severity and number of his seizures. He takes different types of medications, some of them affecting his immunological system, putting him at higher risk of some infections.

Before the pandemic, Bob and his family (sometimes alongside a carer worker) would go to different places, as Bob loves being out. They would go on the bus to the beach, sit in a coffee shop or stay nearby the canal and look at the swans. However, with lockdowns and mobility restrictions, these activities had to stop.

During the pandemic he and his family lived all together under very strict shielding, due to Bob's weak immunological system. His parents and sister were his carers 24/7 during the last two years, given the difficulties to have care workers' assistance during the pandemic. The strict shielding and mobility restrictions, alongside the load of caring and some very complex clinical manifestation of Bob's condition, have had negative impacts on Bob's and his family's mental health.

Given that Bob is now a young adult he lives independently, in a flat very close to his family home. This has had positive impacts on the family dynamics, everybody's mental health, and has also helped to balance caring roles.



Case 5: Naya

Naya is 14. She lives with her parents and two of her three siblings. She has three brothers: two older ones and one younger. Her hobbies include listening to music, baking, and cooking. She also loves going on bike rides and rock climbing. This is an activity she does together with her siblings and dad.

She attends a local school and her favourite subject is 'admin' (administration). School is 'going ok' for her as 'grades are steady'. She plans to leave school after fifth year and go to college or university: getting a degree is part of her future plans. Her plans also include having a job which allows her to travel around the world, as she wants to 'see everything'. She does not want to wait until she retires to enjoy her life.

⁵ This is a vascular access procedure in which a catheter is inserted into a blood vessel to allow blood to be extracted or medication to be delivered.

Naya was diagnosed with juvenile arthritis and uveitis early on in life. Her main symptoms are joint pain, mobility limitations, and sometimes fatigue. She has also experienced some intermittent digestive symptoms, which are now relatively under control. She is under different types of medication, some of them to regulate her immunological system. During the pandemic, she experienced recurrent flare ups of her symptoms, even during the summer, something that she found strange, as flare ups most frequently occur over the winter. She often had to miss school because of pain with doctors and psychologist being not supportive.

The interviews and data analysis

Participant uptake, interviewing, and data analysis was a concurrent process. All interviews were conducted through Zoom videocalls (via the researcher's university account) between March and May 2022. Some participants also talked about their experiences through whatsapp texts, sending voice notes and emails. Each online interview lasted between 40 and 90 minutes.

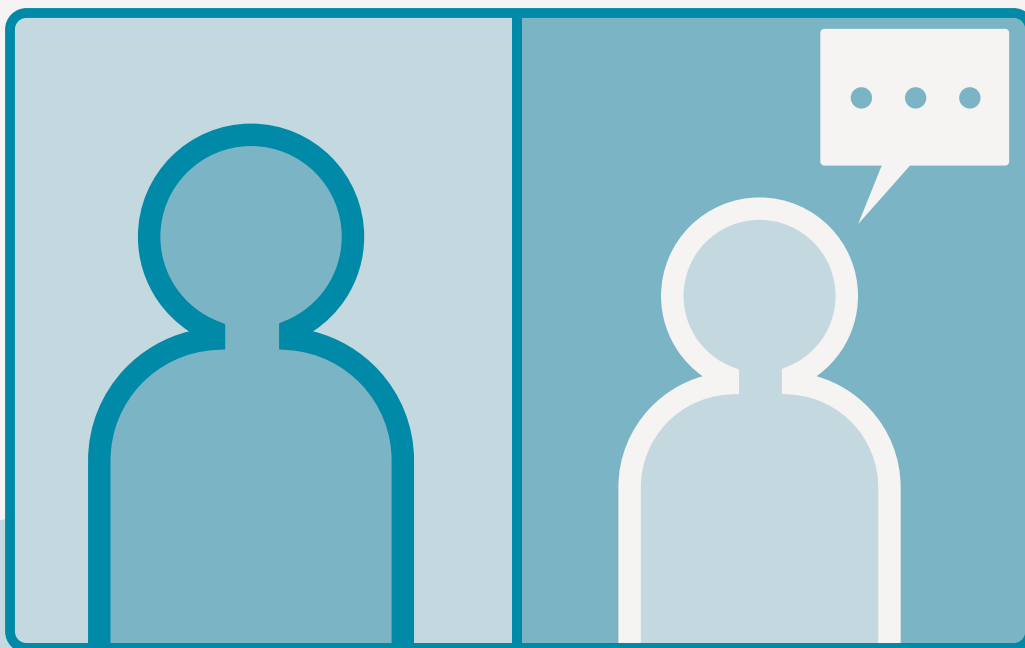
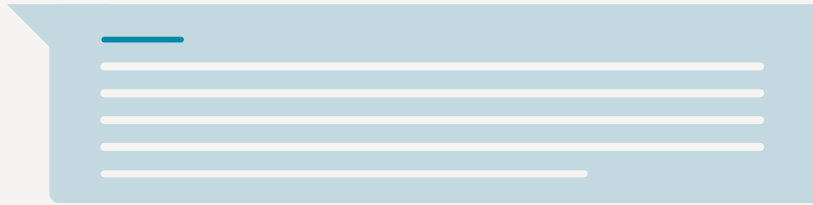
All families received a £10 Amazon e-gift card as a thank you for their time. This was something particularly appreciated by children, young people, and their parents. Compensation, incentives, and tokens of appreciation are commonly used by researchers across different disciplines, with now more evidence showing that this does not represent an unethical research practice (Division of the Vice-President, Research & Innovation, 2022; Halpern et al., 2021; Pieper et al., 2018).

Interviews were recorded with previous agreement and consent from the participants. Although the content and structure of interviews varied with each participant (depending on their own preferences, experiences, etc.), the topics discussed in the first interview commonly included everyday routines, hobbies, family structure, children's medical conditions and treatments. Powerpoint presentations with visual prompts, questions, and 'Miro'⁶ post it notes were used to spark conversations over the three sessions. Being aware of the fatigue associated to the use of screens with one of the participants (Emma), some creative tools (body maps and a game) were sent to her mum's email. These were printed out and completed (in person) alongside her mum, who returned them to the researcher afterwards.

Common themes in the second interview included changes in health and social care services as a consequence of the pandemic, what children, young people and carers liked and disliked about those services, and how information about state entitlements and supports was accessed and shared. Reflecting the participatory character of the study, children, young people, and carers also talked about areas for improvement in how health and social care services and supports could be improved. In the last interview, participants shared some of their ideas and proposals for change through creative works using 'Miro' and recording a podcast.

⁶ Andrea (Bob's mum) explains that communication with his son is mainly receptive. This refers to the process of receiving and understanding a message from another person. In the case of Bob, it is the ability of the other to understand Bob's needs and feelings without the use of verbal language.

Interview recordings were transcribed (not verbatim) by the researcher and participants' stories analysed by themes. Both digital and handwritten mind maps were used to develop a thematic framework from the participants' accounts.



Findings

Section 1: Participants' Experiences with Healthcare

This first section presents participants' accounts and stories of how health services closures and other measures related to the pandemic had different impacts on access to healthcare, their health and wellbeing.



Healthcare services closures: primary, secondary, and tertiary care

The availability of health and support services for children and young people were reduced, or suddenly stopped, at the start of the pandemic, with some services resuming partially over the course of the pandemic (Scottish Government, 2021). Reflecting this, all children, young people, and carers interviewed reported abrupt shutdowns of health services within their localities. Children and young people's access to different levels of healthcare was affected. These included primary care services, such as appointments with gps, physiotherapies, occupational therapy, or dental care, but also secondary and tertiary types of care, such as appointments with consultants and surgical procedures.

The majority of participants reported not receiving any notice about decisions on closures, neither being contacted by services to inform them about what they should do to book appointments and access their regular treatments. Instead, they were the ones who had to make the first initial contact and ask for this. For example, in view of not having access to an ophthalmologist who should regularly monitor her daughter's glaucoma, Kristi's mum asked a local optician to measure Kristi's eye pressure.

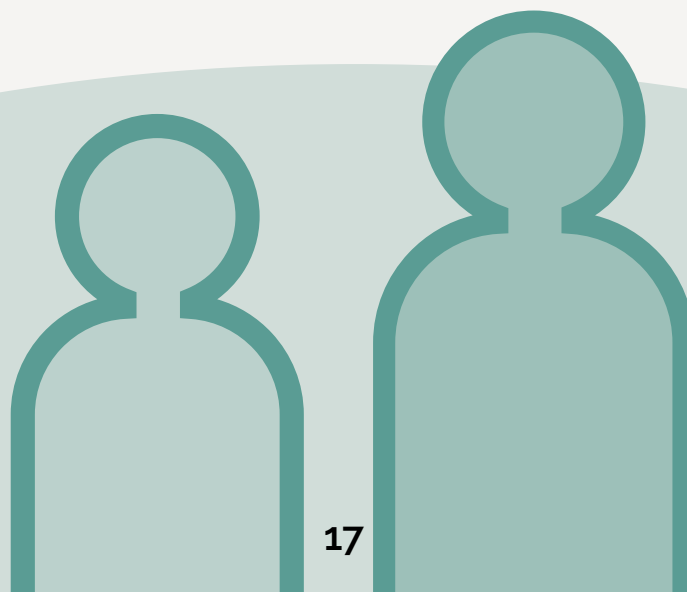
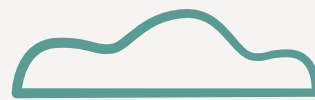
Closures of health services meant that children and young people with complex health conditions did not have access to regular treatments, therapies, and check-up appointments, with negative impacts on symptoms control and progression of their health conditions. For example, Matt a 13-year-old boy with cerebral palsy and his mother, reported not having access to Botox injections during the last two years, which led to a worsening Matt's symptoms:

Mum: 'It's been two years now and he hasn't got Botox ... he should've got it in February 2020, August 2020, February 2021, August 2021, and February 2022, but they cancelled them all...

Matt: It was annoying because you're in pain and you don't know what to do... to stop the pain ... at least for a week...'cause you're... anything you do...you don't know what to do to stop the pain... To go away... to stop it being as bad'

Apart from exacerbating previously controlled symptoms, having no access to timely health services contributed to the progression of children's and young people's conditions. Matt and his mum explained that the poor control of Matt's muscle tone had caused severe joint dislocations and fixed contractures, which ultimately needed to be treated through a complex orthopaedic surgery. Matt's mum explained:

'[...]Botox wouldn't help anymore, because he's been so long without it, so he's got to get his hip realigned... his shorter femur ... breaking his pelvis and realign all that...'



Healthcare closures also impacted on children's and young people's access to regular check-ups to monitor and follow their health conditions. Kristi, an 18-year-old with a genetic syndrome, and her mum, reported that Kristi's regular eye and dental check-ups had been stopped, with high risk implications for Kristi's health:

Kristi: I haven't been able to see a dentist for two years... I think they just forgot that we exist to be honest...

Kristi's mum: she has quite a lot of dental issues because of her condition and that's a bit concerning that nobody's checking your teeth [...] Since the pandemic started, we haven't had any appointments or been contacted by anybody. No letters, notices, or something like that, completely quiet. This is bad as she has glaucoma and needs her pressure to be measured regularly.

Another interviewee also spoke of how her arthritis, which had been kept under control before COVID-19, was exacerbated during the pandemic. She reported significant delays to see her rheumatologist and to get medical treatments during flare ups:

'It wasn't that easy because it's quite difficult to get in touch with them [consultants]. And, like, we had an appointment, but this... they were quite far far away. So we're trying to get in touch with them for a bit and stuff and we eventually got an appointment.'

Naya, 14-year-old girl

Autoimmune conditions such as arthritis need strict management and follow up by consultants (rheumatologists) to ensure control of symptoms and reduce complications. Despite the key role of medical treatments and check-ups in controlling disease progression, rheumatology departments in the UK were functioning at less than 50% capacity during the pandemic, leading to negative health outcomes for those with autoimmune diseases (Nune et al., 2021).

Children and their parents also voiced concerns about the difficulties of trying to access health services for the first time. This resulted in delayed diagnoses and start of treatments, which increased disease burden and further complications. Kati, Emma's mum, spoke of a range of delays and struggles they experienced to have an appropriate diagnosis of her daughter's condition (PANS: paediatric acute-onset neuropsychiatric symptoms). She also spoke of the reluctance of doctors to give Emma appropriate and timely treatment and support:

'It's taken two years to get her diagnosis. And we have no support yet.

We have no treatment yet...'



Apart from services closures, long waiting lists, and recurrent cancellations, there were other factors limiting children's and young people's access to early diagnosis and treatments:

'[...]Matt's surgery was scheduled for May 2021 but it was cancelled, then it was rescheduled for April 2022... [...] his surgery was then cancelled at the last minute. He's having seizures for two years and instead of surgery he was given an EEG⁷ and diagnosed with epilepsy ...'

Lisa (Matt's mum)



⁷ Electroencephalogram: this is a test which records brain electric activity.

Worsening and non-control of symptoms: impacts on children's and young people's everyday lives

Timely diagnosis and access to treatments are not only important for preventing or minimising disease progression, but also key for allowing children and young people to engage with their everyday activities. The participants talked about how non-controlled pain affected their everyday lives in stringent ways:

'[...]The pain stops me from doing quite a few activities and, like, I used to do lots.

Lots of sports as well, at times I just like come away from everything [...] I had to stop that [cycling and climbing] for a bit and because my joints are just really sore, it also stops me from doing a lot of things like going out with my friends or going to school some days... some days it's just really difficult to get out of bed.'

Naya, 14-year-old girl

In Emma's case, not having a clear diagnosis and medical treatment for her condition resulted in Emma being unable to engage with both in-person and online schooling for two years:

'[...]but then since she got her second [COVID-19] infection she hasn't been able to do anything [school-related] not even online, I have asked for a home based tutor at least half an hour a week but we always get no, no, and no [...]'

Kati (Emma's mum)



Therapies: concerns about accessibility and quality

Participants mentioned that some health services, such as appointments with consultants, and other therapies, moved from in-person encounters to online sessions. Although there were some positive views of these services running online, as it implied less traveling times and costs for the families, children preferred in-person encounters. They explained that online consultations were less interactive and engaging, and with the added complication of recurrent technological and connectivity issues. There was also a general perception that some services cannot be delivered remotely, for example those that required the use of medical devices and 'special' procedures. Naya, for instance, explained that her eyes check-up could not be held online as during a usual appointment the doctor often used a 'machine' to check her eyes:

'But my, like, oh uhhh, ophthalmology appointments... they need to be in person, because, like, they have to check my eyes, with the special machine'

Naya, 14-year-old girl

Participants raised concerns about the effectiveness and quality of online physiotherapies and occupational therapies. Those with mobility requirements and chronic muscular and joint pain mentioned that virtual sessions were not sufficiently engaging. This is because therapists tended to send them links to videos and tutorials instead of explaining the activities children should engage with. As Kristi explained:

'[...]they just like send some kind of videos and links to videos. It's kinda boring. When we go in person, the therapists encourage you to do things, give you extra tips. I quite like things in person.'

Kristi, 18-year-old young person

However, concerns about the quality and accessibility of therapies already existed before the pandemic. Children, young people, and their parents spoke of limited access to therapies, particularly physiotherapies. Those with mobility requirements or conditions which needed continuous physical therapies, such as hemiplegia (weakness on one side of the body), paraplegia (inability to move the lower part of the body), and chronic pain, mentioned that appointments were not scheduled regularly for them even before the pandemic. They said they had to 'chase' therapists for appointments, with some therapists 'only wanting to discharge them', and that sessions were too short and repetitive:

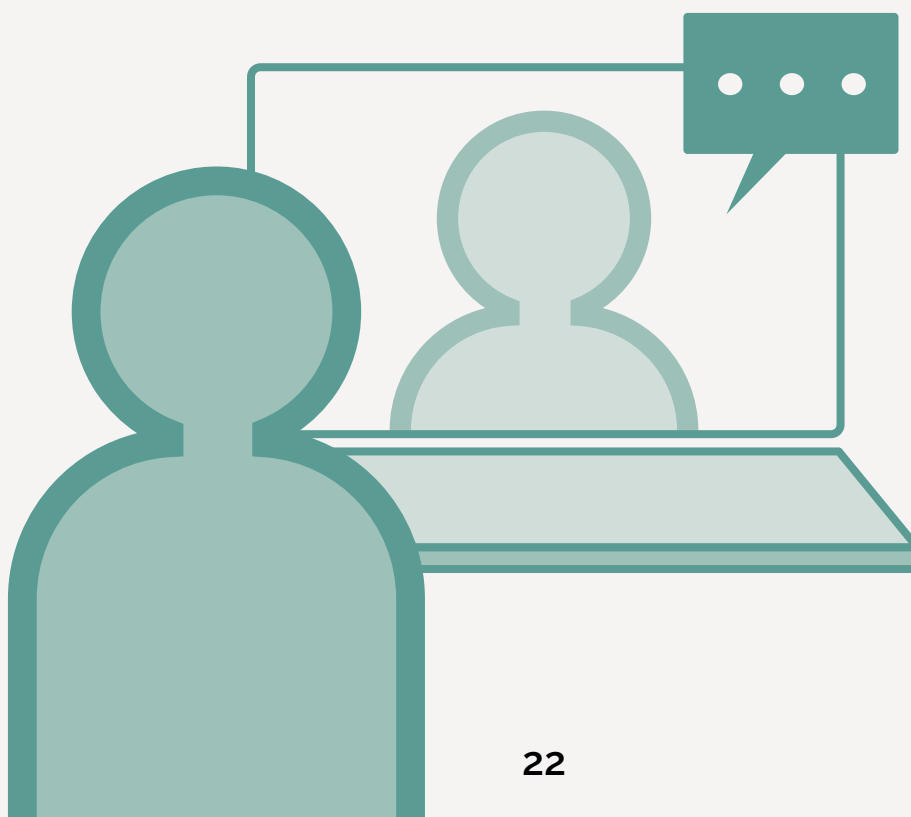
'Physical therapies have been always kinda uhmm, I feel they are only trying to discharge you.'

Kristi, 18-year-old young person

'[...]during the pandemic, it was actually just a senior physiotherapist that worked, we had a couple of Zoom sessions...we would set up the living room and get on the camera and the other ones, but the other... the other ones you never see them... I think physiotherapy now is more paperwork than physiotherapy [...]

[...]and also you can see the physio maybe once a week for four weeks but then you have to chase them up to get more physio...'

Lisa, Matt's mum



Some participants felt that physiotherapy was more patient led instead of having an effective and professional support from therapists. For Matt's mum, therapists only asked if 'they needed anything' instead of having a proactive role in offering support. The pandemic and the use of digital tools seemed to put a greater load on parents who had to lead activities and exercises with their children, although they felt they did not have the skills and expertise to do it. As Lisa (Matt's mum) explained:

'Physio now is more like a patient led physio...so when you get a parent trying to show a child to do physio it's just an absolute lie... because... no child does it and you don't know how to teach them.'

There was a general consensus among children and young people with pain and mobility issues that therapies were especially important to their wellbeing. They talked about how therapies helped them alleviate symptoms, particularly those related to muscular and joint pain. This was clearly articulated by Naya who highlighted the effectivity of physiotherapy and hydrotherapy in alleviating joint pain during flare ups:

'They [the therapists] did a kinda deep tissue massage...that helped in a sense that it was really in my muscles...it...boosted my joints to certain extent, it felt slow and it helped...'

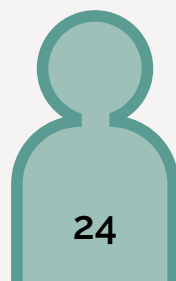
Naya, 14-year-old girl



Limitations in accessing mental health support

There is extensive evidence suggesting that lockdowns and social isolation related to the pandemic have exacerbated mental health issues (mchardy et al., 2021; Patrick et al., 2022; Scottish Government, 2021), also with increases of suicidal behaviour among young people (Wise, 2020). Partially reflecting this data, children, young people, and carers who took part in this research spoke of experiencing significant mental health issues and emotional struggles during the pandemic. Social isolation related to lockdowns, the exacerbation of symptoms, but also stigma and everyday life limitations associated to the poor control of their diseases, raised concerns among young people about their present and future lives. Naya (14), for example, voiced concerns about how her arthritis would affect her future, and wanted to talk about them with someone:

'I have been thinking of how it [arthritis] is going to affect my future...Well, I want to have a job and stuff... because I would like to be an air hostess and I want to be in a position ...in a job that I can travel ...that would be really cool... but i've looked up and done some research and stuff and like... and my cousin's friend, she went through the program [to be an air hostess] and she had asthma and she got kicked out of it because they're like really strict on medical conditions...Because like you're at different altitudes and you're going different places and your sleep schedule gets messed up and stuff with different time zones, so it is really understandable...so I think about like how my medical condition will affect my future ...like 'cause juvenile arthritis is more in young people... i've been told that you grew out of it but 'cause I'm older now and I'm still like going though it... I'm thinking like...am I growing out of it or will I have arthritis for the rest of my life? ... probably I do [...] I'd like that someone can help guide me, to go about it and like have people who I could talk to more about these concerns and stuff...help me through it as well'



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Children and young people felt alone navigating their concerns and emotional struggles and often felt that therapists did not listen to their needs. Similar to Naya, Kristi expressed concerns about her limited social life and stigma associated to her condition. She said she felt worthless and socially excluded. Despite identifying these red flag feelings and looking for some mental health support, she did not get the support she needed:

'In November 2020 my mental health got quite bad and then I told my mum and ... got an appointment and it was like... I don't really know... with some specialist they did like ...uhmm you know they asked all of those questions and then ... well we did that and then nothing really happened after that... I don't get anything... so...'

Kristi, 18-year-old young person



There was a general consensus among participants that conversations with psychotherapists were not engaging, too short, and that their concerns and problems were insufficiently explored. One participant described her last encounter with a therapist as repetitive and overfocused on school life, leaving no room to share their real concerns:

'[...] she was ok... but uhmmm she was just asking me about school, which I feel like... I don't know... I would have liked for her to ask me more about my problems...'



Some parents in particular expressed doubts about the competency and professionalism of some psychotherapists, and the impact this could have on their children's recovery. Although parents were aware that healthcare practitioners 'might not always know all', for them some professionals did not seem 'receptive' to learn about new things. As Kati (Emma's mum) said:

'[...] it's... I don't blame her [the therapist], for not knowing about 'PANS' [Paediatric Acute-onset Neuropsychiatric Syndrome] at all, but I was a bit annoyed that she didn't seem very receptive to going to read about it and learn about it.'



Access to medications

Participants said that access to medications was not significantly disrupted by the pandemic. For the majority of families, medications were appropriately delivered, although with occasional delays and stock issues. Delays were most commonly experienced for medicines dispatched by hospitals, such as anticonvulsants.

Anticipating potential delays, some parents put strategies in place to ensure their children's prescriptions and medicines arrived on time. This included asking for prescriptions ahead of time, phoning pharmacies to check availability of certain medicines and directly contacting manufacturers of medicines produced outside of the UK. Andrea, Bob's mum, said she believes delays were not only caused by the pandemic, but that Brexit also has a lot to do with it:

'[...]I'm not gonna blame only the pandemic...no no, Brexit has a lot to do with this! [delays]...'

Andrea, Bob's mum



Children's, young people's, and carer's trust in health services

Another relevant theme that emerged from conversations with children, young people, and their parents was that of being 'mistreated' by some healthcare practitioners. Patients reported different types of 'bad' experiences with professionals at primary, secondary and tertiary levels of care.

For example, talking about her recurrent visits to hospital, Emma and her mum retold a story of being pinned down for a blood test by nurses, which was deeply traumatic:

'The only thing I can say is that doctors suck!'

Emma, 9-year-old girl

'...they were very busy, they were getting really frustrated because they couldn't get this [blood sample], you know, they needed to just get it done and move on, they didn't have the time to be ... so they eventually just pinned her down to get it [...]'

Kati, Emma's mum

This experience affected Emma's trust in both doctors and nurses, with significant impacts on therapeutic adherence and care plans. Her mum explained that after that 'traumatic' episode, Emma refused to take her medicines and to attend both therapies and medical appointments:

'...now she doesn't trust anyone ... she now refuses to take her medicines, go into medical buildings... we had to meet the physio in the car park the last two times because she wasn't going in...'

Kati, Emma's mum

Although many of the participants said they understand the extreme pressures faced by the health sector, particularly during the first wave of the pandemic, causing their care to be delayed and/or cancelled, there was an event that deeply eroded one participant's trust in the healthcare system. Andrea (Bob's mum) spoke of how traumatic it was for her and her family to be notified that her child would not have access to life-saving care and transport to hospital in case of need. She narrated this event as emotionally 'traumatic', making her question 'what kind of country' she and her family 'were living in':

[...] I remember getting the phone call from the... from the GP about

Making Bob not eligible for resuscitation [...] I was very distressed by that, I was really distressed by that phone call, because it was just like a cold call by a doctor [...] I never met this doctor... I was really concerned about that because it seemed to be quite blanket... not for... not for transport to hospital and not for resuscitation[...]

I said, well, you know, I said: that protocol has to depend on many nuances and I'm not into heroics and ridiculousness... Keeping someone alive, just for the sake of it, but there are many reasons why he might end up in ICU compared to somebody else [...]

I was clear to him ... any decision had to be contextual and I was very strict with that[...]

[...]that call was probably, I mean that was the only point of contact we had with people [from the healthcare system during the pandemic], and it was incredibly traumatic and really poorly thought out'

Andrea, Bob's mum

During the first lockdown and at the most critical point of the pandemic, 'do not attempt resuscitation' (DNAR) notices were applied to groups of people with long term and/or terminal conditions without previous discussion or consent. This order meant that they would not be taken to hospital for life-saving care or resuscitation. The high exigencies of COVID-19 in the early stages meant that health resources were diverted to contain the pandemic with many protocols and decisions representing serious risks to people's rights.

The NHS has experienced incredible pressures over the last two years with some describing the situation as just the 'tip of the iceberg.'⁸ This because the health system has been facing years of important structural issues, which have been inappropriately addressed. The above cases are reflective of a health sector under pressure, despite their rapid adaptation to a worldwide crisis.

8 'An NHS under pressure.' 2022. British Medical Association blogs. Available from: <https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/an-nhs-under-pressure>

Section 2: Participants' experiences of accessing social care services, state entitlements and other supports

This first section presents participants' accounts and stories of how health services closures and other measures related to the pandemic had different impacts on access to healthcare, their health and wellbeing.

Children's and young people's knowledge about social care services, state entitlements and support

The theme of social care, state entitlements and supports emerged as a distant and unfamiliar one for the children and young people interviewed. When asked about what social care services, benefits and supports they received from the Government (such as payments, access to day centres, clubs, transport assistance), the majority said they did not know this information. It was common that the children and young people referred back to their parents, arguing that they might 'know more about that':

'[...]To be honest, that's a thing I think my parents probably know'

Naya, 14-year-old young person

'[...]L: I wonder if you're familiar with the term social worker? Have you heard about them at some point? It's like a person who helps you and your family to have the support you need... for example some benefits that the Government gives to people with medical conditions

Matt: Uhhmm no I don't... to be honest'

Matt, 13-year-old young person

When exploring the reasons for children's limited knowledge of social workers' roles and some of the benefits and supports (e.g. Payments) they received from the government, the complexity of the information available emerged as a recurrent topic. Some children answered that they did not know about services and supports available through social care and security system because they felt that it was a dense and difficult topic to understand. This was explicitly said by one of the participants, who before turning 18 considered 'stuff' related to social workers and benefits as 'just too hard to understand':

'[...]L: Why do you think you were not very familiar with the stuff around benefits and social workers before [turning 18]?

K: I think I just didn't understand it

L: was there any particular reason for not understanding it?

K: that's too hard to understand'

Kristi, 18-year-old young person

As Kristi's account suggests, information about support and benefits that children and young people can claim was perceived as complex and unclear. This perception of complexity might be related to the way in which information about benefits entitlements is shared by the Government and other official bodies. Looking at the Scottish Government website (www.mygov.scot), where key information about payments and supports is provided, information is mainly made available as text. Alternative formats, such as Easy Read documents, videos (with subtitles and BSL/English interpretation), or audio versions of the information are absent from the website. This is problematic, as the information available on the website includes the type of support children are entitled to, the eligibility criteria, assessment processes, and time of assessment: all topics that matter to disabled children and young people. It is worth mentioning that making information accessible and inclusive is at the foreground of the Government agenda (Scottish Government, 2011, 2016). However, the absence of alternative formats suggests that, in practice, children's different levels of understanding and their communication needs are not being adequately considered when making information about state entitlements and supports available to them.

Given that children and young people interviewed expressed not knowing the social care services and benefits they were entitled to and/or were receiving, this topic was explored with their parents. The following section expands on this.

Children's, young people's and carers' access to state entitlements and support: parents' views and experiences

The process of applying for and claiming state entitlements and supports was mainly in the hands of young people's parents. This is not surprising as it is an '*adult with parental responsibilities and rights or a guardian*' who can apply for supports such as Disability Payments on behalf of those under 16 (for example, as outlined in the guidance around the Child Disability payment: <https://www.mygov.scot/child-disability-payment>).⁹

Children's and young people's mothers spoke of claiming mainly financial aids that helped their families afford some of their children's care needs. These included the child disability payment, council tax reduction, mobility assistance, housing benefits, self-directed support, universal credit, and Personal Independent Payment (PIP).

The overall feeling among parents was that financial aids eased the load of caring expenses, but also supported children and young people to have a more independent life. Payments went towards funding services, such as personal assistants, care workers, transportation, and housing. For example, for Kristi, having a personal assistant allowed her to be more independent from their parents, something that her mum also felt was particularly important now that Kristi was as a young adult:

'She's got a lovely PA [personal assistant] who lives near in the village... she helps her doing her nails, they go to the cinema together, horse riding too. I think that it is important now that she's 18, you know ... she might not want to be with her mum at all times'.

Mel , Kristi's mum

Although benefits such as child disability payment helped parents afford some care services and young people's independent living, parents also reported having to draw on other sources (and struggle) to meet all of their children's complex care needs. Private healthcare services, transport, some therapeutic services, and leisure activities such as horse riding, visits to farms, wheelchair football, and holiday clubs were covered by parents' own incomes, fundraising, and/or charities' support. For example, although Lisa (Matt's mum) valued the financial help received from the Government, this did not cover extra costs related to her son's transportation, such as increases in petrol prices:

⁹ Scottish Government. April 2022. 'Child Disability Payment'. Available from: <https://www.mygov.scot/child-disability-payment>

'They [the government] helped a lot and we get pretty much everything... but electricity prices are just going up... you know... we just got ... we just got a big van for Matt and his wheelchair and it's a hundred pound to fill it up every 10 days, you know that petrol... diesel is still high.'

Lisa, Matt's mum

Some parents also spoke of struggling to pay for private healthcare services and some therapies when required. The worsening of children's symptoms and health conditions during the pandemic and the limited support children and their families received from the healthcare system led parents to turn to the private healthcare sector. This is exemplified by Emma's mum's account:

[...]we've had... you know, we had to pay for the private immunologist to get a diagnosis and get her PANS symptoms under control [...] I knew she needed medicine, I knew she needed help, but no one was willing to do it, so that was before we found our private doctor [...]

Kati, Emma's mum

Apart from appointments with private consultants, other private services accessed included alternative medicine therapies, such as acupuncture to treat chronic pain. Despite the benefits children and parents had from accessing these services (e.g. Control of symptoms, clear diagnosis), families were unable to pay for them for longer periods of time:

'i've already paid thousands of pounds for medical treatment...So I can't afford to keep paying for private things [...] we don't have yet the support we need from the NHS.'

Kati, Emma's mum

Factors limiting or enabling carers', children's and young people's access to state entitlements and supports was another key theme that emerged in the analysis of parents' accounts. These were: parents' knowledge of what supports they and their children were eligible for, children's type of medical condition, parents' employment and income status, and their immigration status. Those parents working full time and subject to immigration control were not eligible for carer allowance:

'You can only get carer allowance if you earn under ...I think it's £132 a week ...so because I work full time I'm not entitled to carer allowance, even though your care responsibilities are still outwith your working responsibilities, but that's a benefit for people who don't work'

Mel, Kristen's mum

Similar to Kristi's mum, Andrea, Bob's mum, had no access to public funds because of her immigration status (spouse visa). This is problematic as a key dimension of the human rights model of disability is to protect the inherent dignity of the human being, with all decisions about care needing to be made in line with this. Furthermore, under the Getting it Right for Every Child (GIRFEC) approach, all children and young people are entitled to access the support they need, including their significant others, regardless of their immigration status.

Limited access to state benefits and supports in the case of migrant carers adds an extra barrier to the fulfilment and protection of disabled people's rights. Carers face high rates of exhaustion and burnout, something that is more commonly experienced among unpaid carers (Young et al., 2021). Those individuals with complex medical conditions rely on others for their care and support, therefore carers' health issues and affected wellbeing might have negative impacts on the health and wellbeing of those who they look after.

Expanding migrants' access to state benefits is a clear recommendation outlined in previous reports (Patrick et al., 2022), as most people admitted to the UK from abroad have limited leave to remain and no access to public funds; this includes carers' allowance.

State entitlements and supports: application processes and reassessments

Finding out about the state benefits and supports their children were entitled to was perceived by parents as a process mainly led by them, with some support from social workers. When asked how they find out about the benefits and support they could apply for, the majority of participants mentioned friends, school teachers, and through doing their own research.

Parents and children entered the social security system mostly by chance. Many applied for benefits and grants suggested to them by friends, school teachers or neighbours, with only some being contacted or advised by healthcare and social workers in the first place:

'L: How did you hear of the benefits you access?

Mel: From Kristi's college... Kristi was told that she could apply for SDD [Self Directed Support], then we did in May 2021, and then we started talking with a social worker[...]

Mel, Kristen's mum

'[...]I didn't know anything about social care... I thought it was more related to those people who take your children from you! It was a friend who is a GP who told me, you should apply for the disability allowance'

Kati, Emma's mum



All parents described the process of applying for benefits and being assessed as a *'nightmare'*. Information available on websites and the language and structure of the application forms were perceived as complex, repetitive and *'not user friendly'*. Parents who described themselves as *'well educated'*, also found the application process difficult to complete:

'[...]I think I am well educated and this is just a nightmare!'

Lisa, Matt's mum

Being assessed was described as the most time-consuming stage of the process to access some state entitlements. According to the information available on the Scottish Government website, the time for an assessment to take place might take six weeks. However, parents reported turnaround times of between nine to 15 months:

'It's been a long... very long process... we submitted the form in May 2021... we heard back from them some weeks ago [early May 2022]...It took us a good year to get the funding for Kristen's personal assistant'

Mel, Kristi's mum

'[...]We submitted the form in January 2022 and it's May...we haven't heard back from them yet [...]'

Kati, Emma's mum

For some participants, long assessment times seemed to be related to the loss of forms within the system. Two of the parents interviewed voiced concerns about the loss of their application forms with one being submitted online:

'[...] I got in touch with them and they said that my online form had been lost, and then I had to go through all the process again ...I completed a hard copy of the form, so had to go to the post office and posted it.'

Kati, Emma's mum

Apart from the long waiting times, parents reported that there were no communication channels or ways to track their application. This exacerbated their feeling of being alone with complex healthcare needs, some of them 'out of the system':

'[...]you don't have anybody to get in touch with...it looks like Kristi is out of the system...'

Mel, Kristi's mum

A common concern of parents was that their children will have to be reassessed every two or five years, something that they found inappropriate given the long-term nature of their children's conditions. Parents explained that given the complexity of their children's health conditions, their status of disability would not reverse and, as such, there was no point in going through a re-assessment process for benefits such as child disability payments:

'[...]They are just asking the same questions: Mr. Bob, how has your mental incapacity changed?... Oh my God, really!... what's the point of asking that... come on, it's a genetic condition, his condition will not improve! It's palliative in some way you know... not palliative because he's got a terminal illness but palliative because it's a complex, chronic and progressive condition, with every seizure his brain is getting... you know[...]

Andrea, Bob's mum

Being re-assessed was an opportunity for parents to notice some communication issues and lack of joined up working between health and social care systems. Parents spoke of how being re-assessed entailed long interviews, where repetitive and non-contextualised questions were evidence that information was not shared and reviewed appropriately across both ends. Many parents articulated their frustrations about having to answer the same questions about their children's conditions and the emotional impact that this had on them:

'It's exhausting Liliانا... answering the same questions over and over again [...]'it's exhausting emotionally.'

Andrea, Bob's mum

Communication with health and social care practitioners

Although parents valued the financial support they received from the Scottish Government, they also said that '*handouts*' were not enough. Parents felt that they and their children also needed support from engaging with social and health care staff directly. For example, the majority of parents said they would want to talk to someone, such as a health professional, with whom they can regularly share their concerns and own struggles. They also wished there was '*someone in the system*', a point of contact, who they could get in touch with to double check their care decisions, particularly in emergency instances. This was a feeling particularly common among parents of children with multiple and complex conditions and mental health issues. For example, Andrea explained that having this kind of support available would have made it easier for her to manage her son's home care and his severe seizures during lockdowns:

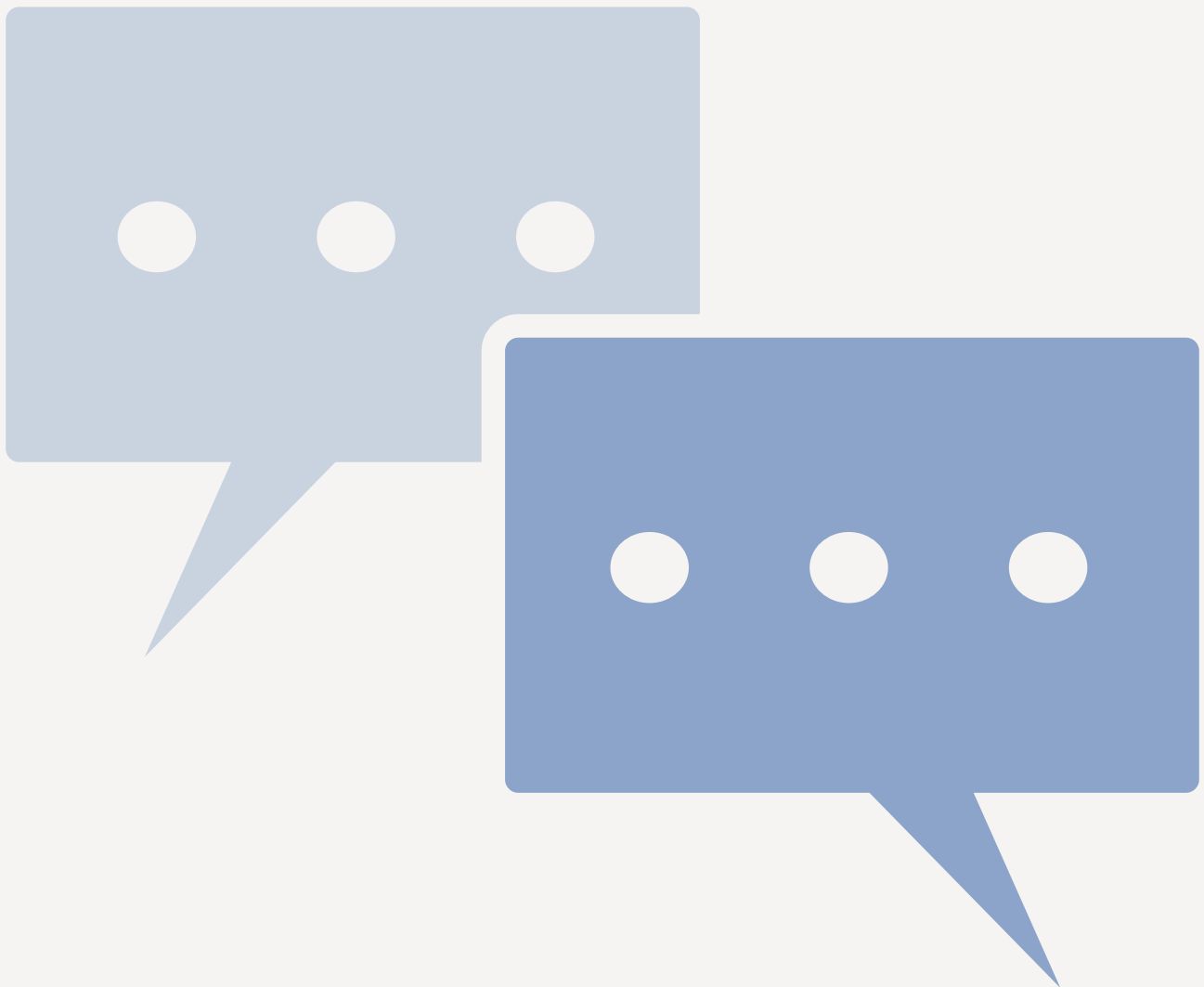
'there are some times that you need to... you wish, you could just pick up the phone... and have somebody who would... like just hear out and say "yeah okay yep that sounds reasonable" [...]'

Andrea, Bob's mum

Like Andrea, other carers felt alone in the process of caring. Some parents felt that managing the complexity of their children's symptoms, alongside Self-directed Support, hiring and training carers, and applying for benefits, would have all been less stressful if they had a more regular and tangible support from a healthcare practitioner or a social worker. Although the majority of parents said disability nurses and social workers were creative, helpful, and supportive to manage these tasks, their workload was extremely high, limiting the support parents and children could receive from them:

'[...] they [social workers] are nice people, they have good intentions and are really helpful, but they are very busy and there's a shortage of social workers... you know...'

Lisa, Matt's mum



A less social model and rights-based model of disability in practice?

The definition of disability has been focused on multiple debates in policy, practice, and academia. From a medical perspective, disability is related to the presence of an impairment, a bodily condition that limits people fully participate in society (Olkin & Reeve, 2001). As such, people's condition/status of disability is based on the presence of a medical diagnosis. Conversely, according to the social model of disability, what makes a person disabled is not their bodily differences but the absence of a policy of inclusion and social structures that allow their involvement and participation in society (Lawson & Beckett, 2021). Similarly, the human rights based model emphasises the fact that those who experience any form of disability have the same rights as everyone else in society. It also puts the individual at the centre of all decisions affecting them (Degener, 2016; Lawson & Beckett, 2021). Disability policy-making in Scotland is based on both the social model and human rights-based model (Scottish Government, 2016).

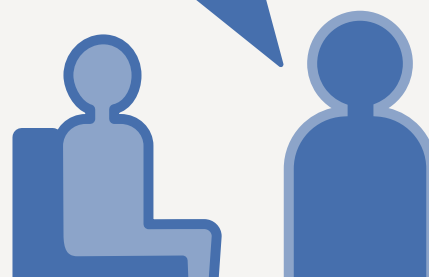
Despite the clear adoption of the above mentioned models by the Scottish Government, children's and young people's access to some benefits and supports were conditioned by the presence of a medical diagnosis. Some parents mentioned having to demonstrate medical certificates of their children's health condition to access some care services and benefits. For example, Andrea, Bob's mum, commented on being asked to show a medical certificate of her son's condition when enrolling him to a day care centre:

'[...]It's like from the day care centre they said if I could get a certificate from the GP that says that he's an adult with incapacity... and it's like ohhh my God! Really?'

Andrea, Bob's mum

Like Andrea, Kati (Emma's mum) mentioned that Emma's medical diagnosis had to be confirmed by healthcare professionals before making a decision about her daughter's eligibility for a disability payment:

'I was notified that they had received my application but four weeks later they called me as they now want to contact her paediatrician and physiotherapist to confirm Emma's illness and limited activity.'



Although the Scottish Delivery Plan to 2021 for the United Nations Convention on the Rights of Persons with Disabilities (Scottish Government, 2016) makes explicit commitments to protect disabled people's rights and enhance their participation in society, some of the cases discussed throughout this report show that this strong policy might not be not correctly implemented in practice. Children's limited access to healthcare and support during the pandemic, their limited engagement and knowledge of the state benefits and supports they are entitled to, and the arbitrary order of non-resuscitation applied to a young person with a complex health condition (Bob), suggest that there is still a lot to do to holistically meet disabled people's needs and to protect their rights.

Summary

The above sections have illustrated, from the viewpoints of five families, how some measures to tackle the sweeping public health crisis associated to COVID-19 in Scotland had negative implications for disabled children's and young people's health, wellbeing, and rights. The above narratives have also shed light on children's and young people's limited knowledge of the state benefits and support they have access to or are entitled to. Their parents' narratives of their experiences with, and views of, the social care system revealed a variety of structural issues within this sector that were already in place before the pandemic.

Recommendations

This section offers a summary of the recommendations suggested by the participants, alongside some points the researcher and the ALLIANCE also consider relevant to maintain at the foreground:

- **Health and Social Care Partnerships and local authorities should make greater efforts to strengthen communication channels between health practitioners, social care providers, and communities. A variety of resources and strategies can be implemented to ensure communication and information delivery is consistent to people's communication needs, skills, and socio-cultural backgrounds. These include producing Easy Read documents, making BSL/English interpreters available to the deaf community, translating documents in other languages, and producing information videos with closed captions and BSL/English interpretation.**
- **Decisions-making processes and responses in both regular and emergency situations should privilege people's dignity and their right of life. Abrupt health services closures and DNR orders profoundly eroded families' trust of both the healthcare system and the Government. As such, all stakeholders, especially medical professionals and social care service providers should urgently address and respond to families' feelings of loneliness and abandonment by the healthcare system.**

- **Offering families the support and company 'from someone within the system' could ease families' feeling of abandonment, and particularly help to recover their trust in the NHS. Having a key point of contact helping them navigate the complexities of care and decision making processes on a more regular and personalised way might have positive impacts on their experiences, also making transitions across the life course easier.**
- **Health and Social Care Partnerships should ensure families have a choice of the type of health and social care services they have access to. Decisions on care need to be sufficiently contextualised, individualised, and made in partnership with children, young people and families' opinions. This recommendation fits with a person-centred model of care, the ethos of the Scottish National Health System, and is also in line with the GIRFEC approach.**
- **Professionals and practitioners within health and social care services should consider individuals' unique life conditions, circumstances, and experiences when making decisions in response to public health emergencies. Paying attention to the particularities of people's lives and experiences could prevent instances of human rights violations, such as the non-resuscitation protocols for those with long term and complex health conditions.**
- **Creating physical environments more accessible and inclusive for children and young people with diverse types of additional needs has to be urgently considered by National and Local Authorities.**
- **For families, it is important that healthcare practitioners take the time to talk with them and hear their concerns, needs, and struggles. Feeling listened to, and like their concerns are addressed, has the potential to improve their experiences with healthcare services and control of symptoms, with positive impacts on their everyday lives. Families are aware of the unprecedented pressures and time constraints that many healthcare and social care professionals face. For that reason, the participants believe that listening to their concerns and needs will allow professionals to offer more targeted and effective care, with positive impacts on therapeutic adherence and control of symptoms, ultimately putting less pressure on healthcare services.**
- **Medical professionals and social care service providers need to make greater efforts to build relationships of trust between them and the individuals and communities they work with. Participants asked for more empathetic behaviours, particularly from gps and consultants.**
- **Training and capacity building programmes with a focus on the particular and unique needs that disabled people have should be offered to both healthcare and social care providers. Particular attention should be paid to both emerging and complex health conditions, such as Long Covid, and those that are less prevalent but that have a significant health burden, for instance, genetic and congenital conditions.**

- **The process of claiming social security benefits, including application forms and reassessment processes, should be carefully reviewed and potentially restructured by Social Security Scotland and the Department for Work and Pensions. Participants recommend more straightforward, concise, and succinct forms with less jargon and technical language. Also, the length and necessity to be reassessed should be determined on an individual basis.**
- **Health and Social Care Partnerships need to make greater efforts to make effective communication between health and social care systems a reality in practice. Taking the time to read other professionals' notes to construct a more holistic picture of each individual would help avoid asking repetitive questions, particularly during assessments. Strengthening communication across both systems is clearly outlined in the Health and Social Care 'Integration Delivery Principles (CELCIS, Children in Scotland and Care Inspectorate, 2018).**
- **The pandemic exacerbated children's mental health issues, and families hope to see Children and Adolescent Mental Health Services (CAMHS) strengthened and better funded. For them, a shortage of professionals is a barrier that limits their access to the care and support they need. This is something that should be addressed urgently by Health and Social Care Partnerships, National and Local Authorities.**
- **Further scrutiny of children's and young people's understanding of the benefits and supports they are entitled to is a relevant venue for future research and intervention. All stakeholders should allocate funding to conduct research related to this topic.**



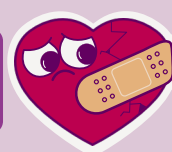
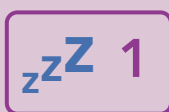
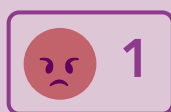
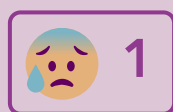
Participants' works

Participants produced some creative works such as posters and a podcast where they spoke of recommendations for future changes and further details of their experiences. We present some examples of their works in this section.



Being a carer is a 24/7 job with no paid holidays and no sick days. It is absolutely exhausting and I don't have the support of my family at the moment. Therefore I am doing it by myself and I'm tired and frustrated and struggle to get time for myself.

I would love for someone to be able to come to our home and even just sit with Emma for an hour so I could do the grocery shopping or take a shower or even just watch a movie! Just one hour a week would be so wonderful. Social Care have agreed to do a Carers Assessment for me but because they are so stretched and under-resourced, they agreed this in January 2022 and now it is May 2022 and they aren't even close to be able to support us yet



A section of Emma's and Kati's poster

Kristi's poster

If I could change something about my healthcare, what would I change?

Doctors listen to you

Occupational therapy

I wanted to learn to put my hair up but I was sent links to youtube videos of someone who could use both arms

In Nov 2020, my MH¹⁰ got quite bad...

Mental health support, I don't have!

How things could be better with dentists appointments?

Professionals should have checked in because I felt abandoned

People with dental problems should be prioritised for appointments

If I have a lot of money...

If I had more money I would buy my own horse and all the extra stuff that comes with having one

My eye pressure was not measured (glaucoma) we didn't hear from them

I would like to have more of...

More help with managing money now I am 18. It upsets me and makes me worried I might pay for the wrong thing

Consultant:

she's truly nice and can explain things

I like online appointments

I get quite stressed in person!

It's quite hard to take in if there's something bad

the optician should have checked in to see if there were any changes to my eyesight

Naya's poster

Delays related to your injections (flare ups)... it was tricky to get in touch with the doctor... how these delays could be avoided in the future? Longer what's it should be done in place, appointments.

If the doctors have more time to speak with their patients and get the full big picture as to what's going on with their health then I think there would be a less delay in appointments due to them being able to put a plan in place for them.

If doctors really take the time to listen, explain and help patients through whatever they're going through because it can be really confusing and stressful with so much going on at once i.e. health, school and just day to day living.

Do you agree to see your consultant every 6 months instead of 3 months as it used to be?

I feel as though I need appointments more often due to my flare ups being regular and for a long period of time. I feel like I need a little more attention towards my joints right now than my eyes.

What kind of support you would like to have from the healthcare workers?

To give a little more time and variety to the sessions and more sessions in certain block i.e. hydrotherapy.

What do you think is missing from your care?

Someone to talk to openly and for them to listen to me and help guide me through the problems.

Conclusion

Drawing on disabled children's, young people's and carers' own accounts and narratives, this study explored the impacts of the pandemic on their access to healthcare, social care benefits, and other supports. We particularly heard about the negative consequences of healthcare closures and limited support on children's, young people's, and carers' lives. The pandemic and lockdowns uncovered complex health inequalities, issues that have a stringent and more negative impact on those with particular health and social care needs.

A focus on children's and young people's own perspectives, rather than accessing their opinions by proxy, has provided a nuanced picture of the mental, social and physical costs of delays and failures to meet their needs. This study therefore represents a significant move forward in producing research with children and young people from groups that have been extensively overlooked across several domains (academia, clinical practice, and the third sector). The recommendations that participants have outlined throughout their narratives offer valuable ideas that should be considered in policy and practice. This is consistent with Scotland's National Action Plan for Human Rights (SNAPHR). 'Real change for children and young people can only happen when adults listen to them and act on what is heard.'¹¹

Policy on disability in Scotland has a strong influence from both the social model and rights-based model of disability. However, this study has provided some examples that raise questions about the extent to which this policy is implemented in practice. Participants' narratives about the need to demonstrate medical certificates and justify medically their experiences of disability speak of a medical model of disability that is still dominant in both health and social care systems.

Also of note is that despite the range of social care and social security entitlements children and young people have access to, their understanding and engagement with this aspect of their care and support is limited. This has implications not only on their experiences of accessing child services, but also for their transition to adult services. More research and investment to ensure that children and young people have an understanding of the systems they can access to receive support is needed.

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¹¹ 'Children's rights protections in Scotland.' 2022. Together Scotland. Available from: <https://www.togetherscotland.org.uk/about-childrens-rights/monitoring-the-uncrc/>

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About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces, Libraries and Access Panels are also members.

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

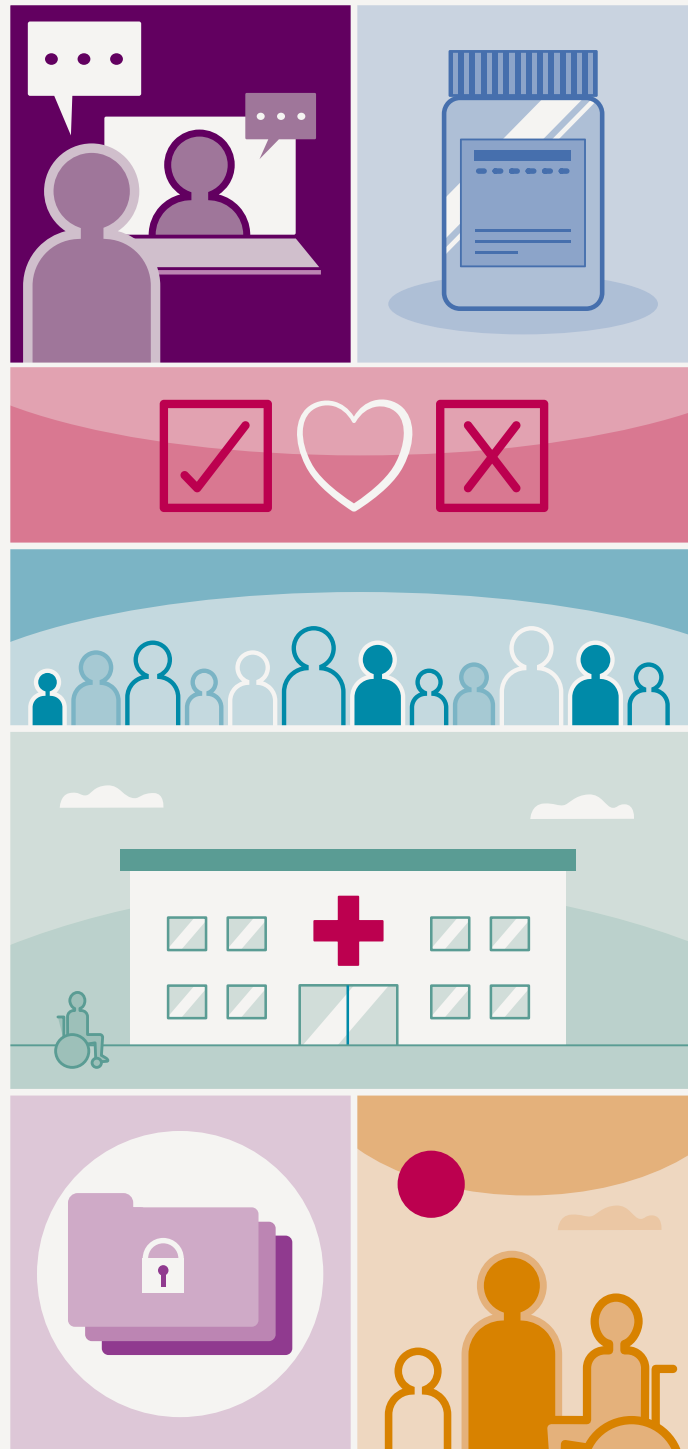
Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims. We seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.



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