'Locked Out':

Digital Disadvantage of Disabled Children, Young People and Families during the Covid-19 Pandemic

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Commissioned by KIDS, a national charity, that provides a wide range of services to disabled children, young people and their families in England.

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Foreword

At KIDS we've seen first-hand the opportunities and difficulties that digital methods of communication have offered and imposed during the COVID pandemic. The velocity of adaptation has starkly illustrated how some disabled people can be left behind – locked out of a world that is accessible to others.

Digital access is no longer a luxury. Across society there are expectations that every child, young person, their families, colleagues, friends, support workers, therapists and even your GP, can access digital technology. Disabled people have a right to share the same spaces.

We commissioned this report for the Pears Learning Hub (1) as a consequence of observing first-hand the barriers that disabled children, young people and families were facing. Together we worked hard to surmount those obstacles so that we could continue to offer access to vital services for disabled children, young people and their families. Understanding the bigger picture and finding recommendations to make change are key outputs that come from our experience and this research.

Done well, digital access can be a real lifeline – enabling access to friendships and vital services including therapies, information, advice and mediation. It has power to make the most difference to these groups, who are more likely to experience isolation and barriers to in-person services.

Digital service design should start with accessibility in mind, co-created with disabled people. The right design and investment could transform and level up experiences as disabled children, young people and their families emerge from lockdown.

We are asking those with the ability to make change to take on board the following:

Policy-makers and funders

- Stop digital disadvantage resulting in permanently locked out disabled children and young people by urgently investing in a recovery programme, designed to increase digital skills of the whole family and on-line access to vital services (therapies, family support etc)
- Include disabled children, young people and their families in existing government programmes, for example on-line volunteer or job support, as a no or low-cost means to tackle digital exclusion.
- Improve accessibility standards so that people aren't locked out from essential information

- Make digital inclusion an explicit part of government policy at every level: from disability policies, strategies and reviews such as the national disability strategy and SEND review;
- Integrate disabled children and families' digital inclusion into mainstream government digital inclusion programmes and include digital in COVID recovery programmes, by listening to the voices of disabled children, young people, their families and expert service providers
- Ensure digital infrastructure is fast, available and affordable for all

People working with disabled children, young people and their families

- Adopt an informal and flexible approach. Improve communications before an on-line session to support people who are less familiar with on-line access. Provide a comfortable digital space that is welcoming and friendly, with clear instructions, but not overly prescriptive in format. Use familiar platforms where possible, and avoid unnecessary functions that might be overwhelming for users.
- Ensure that online safety is paramount, whilst enabling independence. Work alongside families and supporters to promote education about online safety and help them get the right balance between protection and autonomy.
- Take a whole family approach underpinned by an understanding of how one person's confidence and skills in a household affects another's. Share knowledge of how to access digital safely, develop a common understanding of its usefulness and how family back up and support enables children and young people to be confident and safe in digital spaces.
- Support disabled children to access their equipment outside of the school environment when forced to study at home – literally being locked out of access means disabled children are cut off from education. Support children to access equipment outside of the school day so that they can continue to engage digitally and develop their key skills.

Employers

- Break down the barriers between staff with IT skills and staff with expertise in disability. Support all staff with minimum standards (e.g. a 'digital driving licence') so that they can facilitate disabled children, young people, and families in their own use of technology. Build digital skills into recruitment and induction.
- Incorporate staff insights and experiences into employer policies, services and products

Tech developers and companies

- Incorporate user led design and work explicitly with groups and individuals facing multiple disadvantages. Widening the scope of useability is a pragmatic approach as well as a socially responsible one.

Across all sectors we encourage the deployment of digital champions. People who listen out for user's needs. Who can offer support, signposting and mythbusting. Embedding digital champions in your organisation, company or space can move the idea of digital as an 'IT' province and demonstrate commitment to accessibility.

Finally, we urge that learnings are taken from this watershed moment in history. The gap between disabled people's experiences and the expectations of sectors across society cannot continue. We're fortunate to have this opportunity to offer this report as testimonial to the need to level up and free disabled children, young people and their families from being held back in the digital environment.

1) The Pears Learning Hub is a partnership between Pears Foundation and the Disabled Children's Partnership, created to establish the evidence base understanding the impact of the pandemic on disabled children and their families and the charities that support them.

Executive Summary

The Pears Learning Hub is a collaboration between Pears Foundation and the Disabled Children's Partnership to research the impact of the Covid-19 pandemic on disabled children, young people, and families. As part of this initiative, KIDS commissioned this research into digital exclusion and digital disadvantage during the pandemic and evaluate sector responses supporting disabled children, young people, and their families.

This research has included a review of published literature and third sector reports, analysis of publicly available data, a survey of families, a focus group with young people and twenty conversations held with different service-providers and parents.

Measures to control the Covid-19 pandemic have led to the suspension or reduction of many supportive services, reduced access to informal support and sudden home schooling. Charities adapted rapidly to meet the changing needs of disabled children, young people, and their families during the pandemic, with good responsiveness and collaboration. Adapting to digital allowed for support and essential help to continue throughout lockdown and social distancing measures.

Digital disadvantage happens where people do not have the same outcomes from a digital experience - even if they have some use of technology and the internet. Digital disadvantage has negative consequences for social support, information, education, and independence - leading to a vicious cycle for the individual and their family in which stress is increased because goals cannot be reached. To avoid deepening digital disadvantage, it is necessary to better understand the experiences of digitally disadvantaged and disabled children, young people, and families.

Disabled people can benefit from technology, but it appears that some disabled children, young people and families have been disadvantaged during digitisation. Children with sensory impairments, limited dexterity, social impairments, or technophobia are particularly at risk. Other inequalities are relevant – particularly financial resources and language literacy – and these inequalities can be worsened by digital disadvantage.

The pandemic has added to the academic challenges, caregiver burden, and socioeconomic stressors already experienced by disabled children, young people, and families, further widening the gap between those who are digitally included and digitally disadvantaged. Threats to wellbeing in the home environment meant that family members had less time and capacity to support digital engagements. Inaccessible education or public health information created extra stress.

Being able to use digital technology is increasingly becoming a requirement for equal participation in society. Using technology in the right way can mean that disabled

people have more opportunities to participate, online and offline – including for social connectedness, access to information, pursuit of preferred interests, and prospects for independence or personal development. However, individual access, skills, and motivation to use digital are shaped by both the social and cultural context of the individual, and the design and content of the digital services.

Digital competence is developed through access and regular use: confident and beneficial interactions are rewarding, whereas stress and frustration associated with digital can be discouraging. Barriers to digital inclusion include poor design, inaccessible information, complicated formats, unreliable or capped internet connection, the cost and availability of devices and equipment, low familiarity, declining wellbeing and protective or aversive attitudes towards technology.

Interventions seeking to overcome these barriers to digital inclusion must go beyond the simple provision of devices. Families need reliable internet, digital skills, accessible content and platforms, guidance on supporting children and young people, and better knowledge of safety and security online. The internet infrastructure must be improved for the benefits of digital to be fairly available to everyone.

The use of digital has accelerated across society during the pandemic, with service-providers innovating in a range of ways. Service-providers identified strategies including blended forms of communication to support a process of learning around technology, tailoring content around individual needs and preferences, and adding physical components to improve user engagement. Digital service delivery can create logistical and access advantages. But communication through digital does have different qualities to in-person communication.

Hybrid models of service delivery could allow for improved flexibility and logistical advantages in the future. Support workers in the future might increasingly be involved with facilitating user capability to use technology, and so consistent implementation of digital services will require an upskilling of the supportive work force.

Effective digital inclusion interventions are likely to include access to peer support, structured activities with user input, and personalised and long-term technology support. The right to decline digital can be protected and respected: combatting digital disadvantage is about improving choice, so that families and young people who want to access digital are more able to do so. Caregivers and supportive persons need guidance on balancing vulnerability and support needs with the right to autonomy, choice, and independence.

Remaining challenges include identifying and reaching priority groups, evaluating engagement and effectiveness, and supporting staff wellbeing in the move to digital services. Disabled children, young people, and families, including those from minority cultures and other disadvantaged groups, should be involved in the process of

designing services and interventions. Digital disadvantage should remain a prominent consideration in service design and delivery.

Key Findings

1. **Digital disadvantage is related to the personal, social, and wider context** – it is not solely about access to a technological device. The outcomes of digital services for disabled children, young people and families are determined by their functional IT skills, familiarity with the specific platform, and the attitudes and behaviors of people in the immediate social network. Providing devices only is insufficient because this does not acknowledge the other barriers to digital inclusion. Barriers include the design of software and hardware, personal skills, motivation and support within the household, and connectivity challenges.

2. **Services should aim to create experiences of digital that are relational, not remote** – ideally, digital opens the door to support, fun experiences and needed information. The capacity to learn new digital skills requires more basic physiological and psychological needs to be met. Poorly controlled symptoms, pain, or distress are barriers to digital services. Therefore, services that improve health and wellbeing can facilitate digital inclusion initiatives. Services can support disabled children, young people and their families by supporting the development of these pre-requisites to a better experience.

3. **Communication prior to the use of digital can improve the confidence and engagement of disabled children, young people, and families.** For example, professionals can be introduced with 'About Me' information and a picture, before a video call. We recommend that good practice in creating the situation/context/frame of reference is developed with practitioners and shared.

4. **Emphasising informality and allowing time for technical difficulties during the interaction helps to create welcoming digital spaces.** Existing relationships with service-providers can allow for valuable encouragement and personalised technology   support.

5. **Materiality and touch are important aspects of connection**, that are even more essential for some people. Physical components within digital services can improve engagement and helps to combat screen fatigue. We recommend software and hardware be designed to accommodate disabled people, through better engagement with users at the development and design stage.

6. **Where possible, digital services should be designed for use with a smartphone.** Do not rely on large screen sizes or extra functions - most people have their own smartphone, fewer people have personal and private access to a computer.

7. **Plans for education, including special educational needs, should have a strategy for disruptive events in the future.** Pupils could have benefitted from personalised remote learning including hard copy schoolwork and blended lesson plans. Accessibility equipment must not be confined to the school building during future school closures, and parents should be offered training in its use.

8. **Poverty is not the only issue driving digital disadvantage.** People with different disabilities will have different digital experiences. Children with sensory impairment, dexterity issues, and behaviour or social difficulties might experience particular barriers to digital engagement. Priority groups when identifying and addressing digital disadvantage include minority culture or linguistic groups, families without professional experience of using technology, and rural communities who have unreliable connectivity.

9. **Professional teams should avoid working in isolation,** even if they are working remotely. During digitisation, organisations can support their workforce by considering their needs for training, equipment, technology support, and social support. Integrating feedback into practice can improve the staff experience and allows services to meet the changing needs of their users.

10. **Universal design and high standards of accessibility should become commonplace.** Essential information can be provided in different formats suitable for different learning styles. Co-production during design can help to create appealing, relevant, and impactful content that is also accessible to a broad audience. The accessibility of information and essential services must not be neglected during continued digitisation. We recommend that the government assert co-produced standards that must be adhered to in order to make digital more accessible.

Introduction

Background to report

The Pears Learning Hub is a collaboration between Pears Foundation and the Disabled Children's Partnership to research the impact of the Covid-19 pandemic on disabled children, young people, and families, to capture lessons learnt and evaluate sector responses to make recommendations moving forward. As part of this work, KIDS commissioned this research into digital exclusion and digital disadvantage experienced by disabled children, young people, and their families.

Increasing digital delivery has been prevalent in the response to the Covid-19 pandemic. Sectors including education, employment, health care, and supportive services have increased their use of online or virtual formats, particularly during lockdown when face-to-face contact was strictly limited. This has been positive in many areas, with resulting adaptations and innovations that could potentially improve access to much needed support, enabling positive outcomes.

However, people experiencing digital disadvantage are much less able to benefit from increased digital delivery, including some disabled children, young people, and families. Poor accessibility, limited availability of personal internet-connected devices within families, and restricted internet have become more problematic, putting more people at risk of a digital disadvantage that makes it difficult to access education, health services, social support, essential utilities, and public health information.

People may have been frequent users of shared devices and public Wi-Fi, which becomes disabling when public spaces are closed, and service-providers assume each person has ownership of their own suitable device. Whilst being confined to their homes, some individuals have lost access to supportive persons that help them when going online, such that confidence and motivation may have been lost during lockdown, at a time when the need to learn new skills was highest.

Initial reports indicate changing experiences of digital disadvantage and changing needs of disabled children, young people, and families during the Covid-19 pandemic. The digitisation of society means that digital engagement has become more necessary, widening the gap in outcomes between those that can access and benefit from digital services, and those that cannot. Digital exclusion thus creates further disadvantage, and during the pandemic its consequences have been amplified.

Report Aims

This report provides insight into the changing needs and experiences of disabled children and young people and their families through the Covid-19 pandemic, including what has worked in terms of sector and government response, and what priority gaps exist that need to be addressed. This report provides evidence intended to inform policy and practice, as part of the Pears Learning Hub led by the Disabled Children's Partnership and funded by Pears Foundation.

The accelerating use of digital delivery for support services might have exacerbated the digital disadvantage of families with disabled or seriously ill children and young people. This report aims to understand changing digital needs and identify best practice. Understanding more about the impact of digital disadvantage during the pandemic and afterwards is a necessary first step.

Research Outputs

- Defining digital disadvantage and digital exclusion for disabled or seriously ill children, young people, and their families. Describing the impact of digital disadvantage and the barriers to digital inclusion, as experienced by disabled children, young people and families during the Covid-19 pandemic.
- Reporting on experiences of service adaptation and digital innovation during the pandemic.
- Using case studies to describe best practice examples of supportive digital services.
- Making recommendations moving forwards to prevent further deepening of disadvantage experience by disabled children, young people, and families.

Methods Used

- Review of published literature and third sector reports.
- Use of publicly available data and freedom of information requests. Learning from families with a survey panel and from young people with a focus group.
- Learning from service-providers and parents with one-to-one conversations.

Part 1: Literature Review

What is Digital Exclusion?

Digital exclusion usually refers to people who do not use or have very limited use of the internet. It has been defined as relating to device ownership and internet access, the accessibility of online materials, digital skills or knowledge, motivation and confidence, and financial and time resources (Sanders, 2020). Digital exclusion was initially a binary concept, with 'digitally excluded' referring to those who were objectively offline, without any technology skills. Scholars discussed a digital divide emerging between the 'haves' and 'have-nots' in terms of computer ownership, leading to a focus on affordability and access (Carmi & Yates, 2020; Compaine, 2001). The concept was extended by exploring differences in how people find information online (Hargittai, 2001), going beyond technical equipment to reveal relevant factors related to an individual's skill, their autonomy of access, characteristics of the available social support, and their typical types of internet use.

Digital exclusion is not simply arising from a lack of individual skills but can be understood as a lack of digital autonomy, shaped by structural and contextual features. Critical factors to digital inclusion are individual access, skills, confidence, and motivation – understanding these factors requires insight into the social, economic, and cultural context (Faure, Vendramin & Shurmans, 2020). Socio-demographic factors are known to impact on internet use, most prominently the individual's financial situation and their level of formal education (Scholz, 2017). These factors intersect disproportionately with disability and disability-related barriers to education or employment: the most recent Family Resource Survey indicates that one in four disabled families have relatively low income. Disabled people in the UK are less likely than non-disabled people to obtain a university degree and are less likely to use the internet daily (see part 2).

Over the last twenty years, digital exclusion has been shaped by the geographically irregular development of internet connection, the growth of e-commerce and shifts in audience behaviour, changing workplace expectations, and increasing 'digital by default' service delivery (Hargittai & Hseish, 2013; Vartanova & Gladkova 2019). Digital exclusion can be explored in relation to access to internet infrastructure, adoption of internet-enabled technology, conditions of economic marginalisation, and historic forms of oppression. Negative digital experiences can contribute to digital exclusion - including those arising from insufficient internet, digital illiteracy, elite internet culture and online predation or cyberbullying (Gangadharan, 2021).

Disability is often overlooked during investigation into digital exclusion (Scholz et al, 2017). A survey across European countries, reported that disabled people are significantly less likely to have internet access at home, even after controlling for other factors. In the UK it was estimated that 81% of non-disabled people have internet

access at home, but this was the case for only 60% of disabled people. Disabled status appears to exacerbate the effects of socio-demographic factors on internet use; particularly financial difficulties, living alone and old age (Scholz et al., 2017). Accessibility is a crucial consideration – digital technologies and digital literacy programmes tend to be designed for non-disabled people (Carmi & Yates, 2020). The design of technology and the pace of change can lead to the digital exclusion of people with impairments (Dobransky & Hargittai, 2016). Inequalities exist in device ownership and online activities of disabled people; yet there is limited quantitative or generalisable evidence on internet literacy of disabled families and young people.

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Activities and barriers in the offline world have implications when going online, and vice versa – barriers in the digital world have consequences for life offline. Confidence and self-efficacy can change between different surroundings and across different interfaces or platforms, such that the context of the digital interaction shapes the capabilities of the user and their digital experience (Goodman-Deane et al., 2020). The same person could be highly experienced in one activity but lacking confidence and understanding in another. Therefore, digital exclusion and digital inclusion are not static binary phenomena – we are not simply 'in' or 'out' of the digital world, but instead our digital experiences are dependent on the situation and the task. However, it is crucial to explore how digital barriers can compound existing marginalisation, perpetuating the differences in outcomes between disabled and non-disabled people via a process of digital disadvantage.

Social Inequality leads to Digital Disadvantage

Digital disadvantage can be understood in relation to other inequalities within society (Dobransky & Hargittai, 2016). Compared to the most privileged groups in society, people with economic difficulties and from minority groups are less likely to use the internet and have less autonomy in their internet use. Unequal access and digital disadvantages have negative consequences for society because the opportunities offered by the internet are not available to everyone in the same way. The internet offers the possibility to improve one's life, but in a virtuous cycle, such that people with existing social advantages become more fortunate because they gain offline advantage from online engagement (Ragnedda, 2017; van Deursen & Helsper, 2015). Therefore, inequalities related to ability or disability, age, education, gender and socio-economic status are exacerbated in a digital society (Carmi & Yates, 2020).

UK evidence suggests that limited or non-users of the internet share some characteristics around age, education and deprivation levels, with socio-economic status being particularly relevant (Yates, Carmi, Lockley et al, 2020). Inequalities in internet use are demonstrably linked to offline social inequalities; but people with

physical, cognitive, or sensory disability have digital needs that may be obscured by categorising all disabled people as one, sometimes together with other disadvantaged groups (Newman, 2016). Disabled people are over-represented among those who are digitally disadvantaged. Importantly, there is variation between different disability groups in their digital access, use, and the barriers experienced. Research suggests those that are most likely to be digitally disadvantaged are people who have difficulties leaving their home, people who are blind, people with multiple disabilities, and people with language or cognitive impairments (Johansson, Gulliksen & Gustavsson, 2021).

Providing devices through schools is sometimes considered an equaliser to socioeconomic barriers, but recipients may have to rely on family know-how and physical assistance for digital engagement. Low levels of knowledge and expertise in the home environment leads to setbacks, loss of motivation, and possibly even avoidance of future opportunities for digital use (Newman, 2016). In particular, technology interfaces that are difficult to use for disabled people demands input from supportive relationships. This aggravates existing inequalities because the availability and capability of these relationships is unequally distributed (Carmi & Yates, 2020). For disabled young people, parental characteristics that increase the risk of digital disadvantage are low education level, low socioeconomic status, employment experience that does not involve digital, having no interest in or actively rejecting technology and living in a remote area (Faure et al, 2020). The type of work can be more influential on digital capability than the person's age or their level of employment (Yates & Lockley, 2020).

Digital access and digital competence are both relevant to the experience and outcomes of digital activity. Together these concepts can be referred to as digital capital. Research in the UK shows that the availability of social support is improved through internet access and use, because online interaction reaffirms existing social ties and enlarges existing social networks, which reinforces continued online activity (Ruiu & Ragnedda, 2020). This research shows digital capital (access *and* competence) influencing social communication frequency and the nature of relationships, whereas people without digital access or with limited digital competence are more vulnerable to social isolation and loneliness. Digital disadvantage is understood to be emerging from and reinforcing other inequalities in society – therefore efforts to improve social exclusion should understand the relevance of digital disadvantage in modern society.

Digital Inclusion and Participation of Disabled People

Digital inclusion is broadly defined as ensuring all people have equal opportunities and skills to access and benefit from digital technology (Carmi & Yates, 2020; Pawluczuk, 2020). Digital inclusion incorporates both the skills to use technology and the opportunities to use those skills (Barlott, 2019). Digital technology can benefit an

individual's capabilities, educational experiences, and reduce caregiver burden, such that disabled people are a part of society that might benefit the most from digital inclusion (Khanlou et al., 2021). Children and young adults with disability-related cognitive and communication challenges can be supported to live more independently by facilitating their access and use of digital technology (Schall et al., 2016). Accessibility features, assistive technology, and support persons have important roles to play in this process (Buchholz, 2020).

There is low usage of assistive technology due to inadequate assessment, lack of awareness, high cost and insufficient funding, such that technological supports are underused or not successfully adopted (Boot et al, 2018). Additional barriers include the lack of training and support provided to teachers and parents, the affordability of equipment, poor follow-up from technology support services, insufficient personalisation and inadequate infrastructure for operation within education or home settings (Khanlou et al., 2021). These barriers exasperate existing challenges for participation and can result in users becoming unmotivated and abandoning technology equipment.

Digital inclusion can support the social connectedness, self-expression, education, and access to employment of disabled people (Barlott, 2019). Technology enabled communication, for example during online interactions, can allow disabled people to construct and express their own identity and personality, leading to increased confidence and emotional openness (Tsatsou, 2020). Being included in digital technology 'opens the door to possibility' in young disabled people's lives, in that it generates new opportunities and choice for connection with others, the pursuit of personal interests, and self-directed activities of daily life (Barlott, 2019).

Autonomy and independence supported by digital technology can be especially advantageous for transition age groups as they move towards adulthood. Achieving these benefits requires the development of digital literacy, and increased opportunities for digital use outside of school (Khanlou et al, 2021). Moderation of technology by family members and reliance on them for assistance can facilitate online possibilities but can also limit agency and constrain opportunities for social connection (Barlott, 2019). Attitudes, skills, and behaviours within supportive relationships are relevant - it can be challenging for support persons to achieve an appropriate balance between protection and autonomy online (Khanlou et al, 2021).

Smartphones are increasingly the most important device for accessing the internet among some groups of disabled people. This could be related to their convenience, accessibility features, straightforward routes to repair, and options to integrate with other mainstream devices (Johansson, 2021). Disabled children and young people may prefer to use the accessibility features of mainstream technology than to use assistive specialist technology - to contribute to social acceptance and normalisation, it is important that technology does not separate disabled and non-disabled people, aesthetically or culturally (Tsatsou, 2020).

Digital technology could potentially mitigate the barriers faced by disabled people in many areas, including education, daily living, financial independence, and civic participation. The benefits of the internet depend on the amount of use and online expertise - digital participation has enabled some young people to exercise their voices as engaged citizens, but this empowerment is limited to some sections of society (Pawluczuk, 2020). Many young people in the United Kingdom lack personal access to a computer or the internet, have poor functional digital literacy (and therefore low employability skills) and experience perceived powerlessness online as well as offline (Wilson & Grant, 2017). Today's digital infrastructure leads to disadvantage reflecting yesterday's patterns of inequality: related to ability, class, education, gender and wealth.

Being able to communicate through digital technologies is increasingly a prerequisite for equal participation in society. However, disabled people criticize low accessibility, poor usability, and unnecessary complexity in the design of technology (Tsatsou, 2021). As well as identifying and eliminating existing barriers, we can prevent new barriers from being introduced by prioritising accessibility and implementing universal design (Johansson, 2021). Inclusive design, as a methodology, creates products that can be used effectively by diverse groups of people. Involving disabled young people in the design process of digital products and inclusion initiatives is advantageous as an opportunity for participation, to encourage critical discussion of project objectives and digital inclusion concepts, and to elicit a sense of ownership and connection among participants (Pawluczuk, 2020).

Technology Acceptance and Digital Refusal

Digital technologies do not spontaneously emerge and become instantly adopted - technology must be accepted by users. Models of technology acceptance tend to focus on two factors: perceived usefulness (belief that using the technology will enhance the task experience or improve its outcomes) and perceived ease of use (belief that using the technology will be free from substantive effort and risk). Perception of usefulness and ease of use are derived from the social context, and therefore the individual's network or community influences technology acceptance or refusal. Technology acceptance as a process, rather than a single event, contributes part of the context in which digital disadvantage can be understood (Vassilakopoulo & Hustad, 2021).

Technology can induce stress in the user. This is pronounced in situations of uncertainty, information overload, application multi-tasking, constant connectivity, continual relearning, and/or future-related insecurity (Molino, 2020). Acquisition of digital skills is embedded in past experiences and may be hampered by subjective aspects such as embarrassment from perceived inadequacies (Faure et al, 2020). High self-efficacy is associated with more enjoyment and use of technology, whereas low self-efficacy reinforces a reluctance to engage with technology (Chao, 2019). Literature also reports on the relevance of fear, specifically that high levels of

technology usage by children and young people might adversely affect developmental processes or put them at risk of social dangers such as cyber bullying (Hargittai & Hsieh, 2013). It is important to understand what factors are most important in explaining how technology creates stress in specific users, and how the psychological and social context can mean that users are unable to endure technology frustration (Molino, 2020).

Since digital participation requires compliance with algorithmic data collection, users may feel powerless to privacy implications, having to trade their personal information in the name of digital (and thus social) inclusion (Pawluczuk, 2020). Young people who are digitally disadvantaged may lack understanding of how their data is stored and shared, leaving them at greater risk of unethical practices associated with digital economies (Pawluczuk, 2020). Considerations of privacy and the consequences of surveillance can be of heightened concern for members of marginalised communities, resulting in their affirmative rejection of the forced adoption of technology (Gangadharan, 2021). In contrast with technology acceptance, this is described as digital refusal. Digital refusal may be a response to negative experiences, including online abuse, or represent an autonomous choice to refuse digital services and technological communication.

Parents who perceive their child to be vulnerable to harm online may be over-protective, particularly of disabled children (Newman, 2016). This introduces another potential barrier to digital inclusion, of gatekeeping by caregivers. Developing digital skills requires the opportunity and ability to access digital technologies and the internet, that the content itself is accessible and age-appropriate, and for supportive persons to enable and encourage the activity. This indicates distinct areas, each of which can become a barrier resulting in digital exclusion or digital disadvantage (Chadwick et al, 2013):

- → Access to an internet-connected device
- → Digital literacy skills
- → Universal design of websites (with integration for assistive technology or accessibility features as needed)
- → Gatekeeping by caregivers

Having the digital skills required to understand and create content online gives opportunities for self-expression, increases personal social networks, and permits individuals to find the information they need for both online and offline activities. However, digital access does not equal digital skill development (Lewchuk, 2020). Digital literacy deficits put individuals at a disadvantage because they are less able to benefit from the interactivity of the digital world, confining them to the role of passive consumption. It appears that most adolescents with chronic health conditions enjoy reading about others' experiences, but refrain from contributing their own stories (Kohut et al., 2017). Thus, while technology can present the possibility for increasing independence, communication, and social participation, devices do not in themselves

enhance the lives of young disabled people. Those who benefit the most from technology's potential have the internal ability and motivation to participate, significant ongoing support (training and technical adaptation), and regular opportunities available to shape their own technology practice (Isaksson & Bjorquist, 2020).

Covid-19 Experiences

The Covid-19 pandemic has disrupted daily lives and accelerated the increasing use of digital platforms for essential services including education and healthcare. The lockdown ordered to control the spread of the virus has drastically limited the support available for disabled children, young people and families. There was a lack of reliable information provided to disabled families, public health information was not available in accessible formats, and disruptions to normal routines and to food supply was likely to exacerbate challenging behaviour (Yates & Dickinson, 2021).

Survey and interview research in the UK and other countries indicates the negative impact of lockdown on mental health and physical activity of children and young adults with disability (Theis, 2021). Negative effects of the lockdown on child's wellbeing were reported, but experiences and their consequences differed markedly between families (Cacioppo et al, 2020). Children with little physical activity had greater psychosocial problems including challenging behaviour (Tso, 2021). Reduced social contact and loss of physical activity was associated with more negative behaviour, including aggression and self-harming behaviours and regression in communication and social skills (Theis, 2021). Low levels of social interaction were associated with impeded or reversed development of communication skills and parental perceptions of helplessness (Cacioppo et al, 2020). Physical and mental health problems of the child had a large impact on parental stress (Tso, 2021). Parents report that concerns about their child's development and their child's deterioration during lockdown has caused them greater distress than fear of Covid-19 infection itself (Grumi et al, 2021).

Parents of children with special educational needs were more likely to experience elevated stress during school closures and interruptions to rehabilitation services (Tso, 2011). Student learning during the pandemic has been inhibited by low digital competence, lack of personalisation, and the phenomena of screen fatigue (Ewing & Cooper, 2020). Poor student engagement, lack of reliable internet connection, and low access to appropriate devices have been moderate or significant barriers to learning (Scully, 2021). Disabled students are reported to be experiencing disproportionate impacts to their academic, social, and emotional development due to the Covid-19 pandemic (Toste et al., 2021).

There is the potential that consequences of lockdown for disabled children and young people could be long-lasting and made worse by the effects of digital disadvantage (Cacioppo et al, 2020). The disruption of daily routines and the system of care could noticeably impact on the mental health of individuals and the relationships within families, leading to further impediments for digital competence. Communication and

cognitive factors are critical barriers to the use of online services and education platforms - therefore the pandemic is expected to amplify the academic challenges and socioeconomic disadvantages already faced by disabled children, young people and their families (Ameis et al, 2020).

Conclusion

The distinction between the online world and offline world has become increasingly blurred over time, as more 'real-world' activities include digital components, and more 'digital' activities lead to real-world consequences (White, 2020). Similarly, the divide between people who are digitally included and digitally excluded is becoming less identifiable. Instead, many people are online, but markedly disadvantaged in achieving the offline outcomes of their digital endeavours. Digital disadvantage people experience barriers related to device access, reliable internet, digital skills, accessible content and platforms and gatekeeping by support persons.

The emerging literature on digital inclusion for younger disabled people emphasises the critical need to look beyond individuals, to recognise that daily practices and social context shape resources for digital engagement (Newman, 2016). Changes to society since the beginning of the Covid-19 pandemic have led to a heightened significance of digital access and intensified the consequences of digital disadvantage. Interventions should enable individuals to navigate their daily lives, online and offline, overcoming barriers to further their inclusion and active participation in society.

Part 2. Use of Public Data Sets

This section presents insights from a freedom of information request made for this project (see appendix 1) and analysis of publicly available population data sets, including the Labour Force Survey (LFS) and Annual Population Survey (APS) of the Office for National Statistics (ONS) and the Family Resources Survey of the Department for Work and Pensions (DWP).

Across all age groups, 22% of people in the UK are disabled. Disability is more common at older ages, but 8% of children are disabled. Of these children, 45% are reported by government statistics to have a social or behavioural impairment and 35% to have a learning impairment.

There are an estimated 1.7 million disabled people aged 0-24 years in the UK.

Outcomes for Disabled People

In the UK, disabled people are less likely to obtain a university degree, are less likely to gain any qualifications, less likely to be employed, less likely to own their own home and more likely to experience domestic abuse than non-disabled people. Disabled people are just as likely to be involved in civic participation and volunteering as non-disabled people. But average wellbeing is significantly poorer, especially in terms of anxiety and loneliness.

The impact of the pandemic has varied between different people, but data suggests that disabled people are more likely to have experienced negative consequences (see appendix 3). Disparities are observed in the impact of Covid-19 on physical health, mental health, and access to groceries, essential items and healthcare. Loneliness and anxiety have increased, with 47% of disabled people now experiencing high anxiety. Access to healthcare should be an area of concern, because 50% reported their medical care has been disrupted or cancelled, and many of these people reported their health had worsened as a result.

This analysis is limited because the ONS does not collect data on disabled status for people under 16. Representative statistics on the impact of Covid-19 on disabled children and young people are not yet available. Outcomes for disabled people in the UK, across age groups are reported in more detail in appendix 2.

Family Size and Resources

The literature reviewed in Part 1 suggests that supportive relationships and financial status have a substantial bearing on children and young people's internet access and

use. LFS does not collect data on disability status for people under 16 years, so the proportion of families with one or more disabled children is estimated, using the Family Resources Survey.

In 2020, there were nearly 1.8 million households consisting of lone parents with dependent children, corresponding to nearly five million people. There were also nearly one million households with three or more dependent children, corresponding to just over five million people in households with 3+ children during lockdown. Of households consisting of a couple with children, ten percent (10%) have a disabled child. Twenty percent (20%) of lone parent households have at least one disabled child - there are approximately 88,150 households in the UK with a single parent and at least one disabled child. The Family Resources survey reports that of all children aged 0-15 receiving care, 70% require continuous care; of young people aged 16-24 years receiving care, 53% require continuous care.

Twenty percent (20%) of lone parent households have at least one disabled child - there are approximately 88,150 households in the UK with a single parent and at least one disabled child.

The Family Resources Survey shows that people living in a family with disability are more likely to have low income than non-disabled families. The percentage of families with relative low income and a disabled person generally increased between 2019 and 2020 (before housing costs, increased from 20% to 23%; after housing costs, increased from 26% to 27%). Across all households, 14% experience food insecurity or marginal food security (pre-pandemic). Households with incomes of less than £200/week are the least likely to be food secure – 74% have good food security.

One in four families living with disability have relatively low income and therefore could be at risk of food insecurity.

Internet Access and Usage

ONS produces statistics on internet access including frequency of internet usage in Great Britain, comparing age groups, and separately by disabled or non-disabled status. Cross-tabulated analysis by age and disability status is not available, and data is not held on the proportion of disabled children living in a household without internet access.

Of relevance is that disabled people (across age groups) use the internet less than non-disabled people (detailed in appendix 3). 84% of disabled people use the internet daily, compared to 91% of non-disabled people. Disabled people are less likely than non-disabled people to use emails, internet banking, video calls, online health information, online medical services such as prescription requests, online learning materials, and online shopping. Differences by age and by disabled status indicate

large differences in internet usage, privacy concerns and security behaviours, and device ownership.

Part 3. Survey of Families

This section reports on a survey panel, led by the Disabled Children's Partnership, and sent to parents with a disabled or seriously unwell child. Multiple surveys over the course of the Covid-19 pandemic and associated restrictions aimed to capture experiences and consequences. An earlier survey panel (n=635) indicated that 72% of families reported their child's Education, Health and Care Plan (EHCP) or Special Educational Needs (SEN) plans had been negatively affected by the pandemic - with 67% getting less or none of the support required.

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The survey sent in April 2021 included questions on education and aspects of digital exclusion. Due to dissemination strategies this sample is likely to be digitally engaged, however, there were clear barriers to digital inclusion identified in the results – see *table 1*.

Parents often described needing to give one or more of their children continuous support with schoolwork. This was more difficult when there were multiple children present. There were multiplied demands on internet connectivity at home, and some parents reported not enough space, or there being too much noise in the home when children and parents are working. Having to purchase new laptops or extra accessibility equipment was an additional expense. Those who could not afford new devices were working with poor quality or broken hardware.

Children may have had access to specialist equipment within the school environment that was not available at home, so they were not able to use their devices and were effectively 'locked out' of their schoolwork. Laptops provided by schools did not always have the required software or appropriate permissions to meet the demands of the online education being provided. Funding was inconsistent in what additional equipment would be included and there were long delays reported.

Provision of learning was not always tailored to the child's needs. This may have increased the child's stress and created additional work for the parent, which they may have felt insufficiently equipped to provide. Children might not comprehend screen learning or be interested in the content provided, they might be fearful of screen engagement, or become overly stimulated and overwhelmed by screen content, leading to distress. Free text answers indicated additional difficulties with virtual

schooling, including tech phobias, the child recognising the device as being for fun only, or the child being confused or distressed by the parent acting in a teacher role.

Working with video lessons or experiencing excessive screen time was described as leading to negative consequences for the child's behaviour, mental health, and eyesight, occasionally creating neck back and shoulder strain. Pre-existing relationships with teaching staff did not necessarily translate into online engagement or personalised communication. Working on paper was more suitable for many children, but printing is expensive, and the materials provided were not necessarily printer friendly. Some parents reported they had requested paper copies from school, but they had not been provided. Other parents reported that schoolwork was only provided in the form of worksheets, and that all interaction had been lost. Some children became more isolated due to a lack of opportunities and support for social interaction, with parents describing social withdrawal or declining communication skills.

Digital platforms used by the school were unfamiliar to parents, and complexity was aggravated by teachers working in different ways and using multiple attachments in providing learning materials. People who are familiar with these platforms might not relate to the difficulties experienced by novices. The survey indicated a need for very simple explanatory guides and the availability of additional technical support for access to home learning. *Table 2* provides more detail on the digital support needs reported by parents and families.

Table 1: Challenges reported via survey to the Disabled Children's Partnership. Four hundred and twenty-one parents participated in April 2021.

Challenges experienced in using technology at home	Proportion reporting this challenge (n=421)	Example quotes from parents
Poor or inaccessible design for people with disabilities	32%	"Not enough age-appropriate disability-friendly apps and programmes." "Sensory overload, blue light sensitivity and too much information being presented."
Internet connection at home is poor or unreliable	31%	"More than one person needing to be online at the same time has caused connectivity issues."
Not enough computers or tablets to use to go online	20%	"Three children at home and two working adults – we don't have five computers at the same time."
Lack of accessibility equipment or other necessary devices	18%	"He needs an adapted keyboard and software. We were refused funding for this."
Cost of data / limited data plans	11%	"The usage has gone up loads and price has gone up."
Too complicated for parents to understand new technology	9%	"It was a struggle to learn new tech. It ended up like a full-time job for me. It was hard work and very stressful all-round."
Takes too much time to learn new technology	6%	"Parenting two children with high needs leaves little free time to have the opportunity to read about new technology and use it."
Other e.g. Challenges in home environment. Child unable to engage with screen. Needing continuous parent support. Negative consequences of screen time for child's health and wellbeing.	37%	"Due to our home layout, my daughter feels a lack of privacy." "Having two children on live lessons at the same time, the noise of one is affecting the other." "She believes school is school and home is home." "Home isn't for learning and my child objects." "My child gets overwhelmed using screens, causing unpredictable behaviour." "She was so overloaded she just shut down or had meltdowns. Too much time spent in one

Cost of printing hard copies. Working with unsuitable devices. Added complexity in school practices		position, intense back neck and shoulder problems and eyesight problems." "The teachers all made access to their work in different ways. It was a struggle to figure out which attachment to open when."

Table 2: Helpful and recommended support reported via survey to the Disabled Children's Partnership. Four hundred and twenty-one parents participated in April 2021 (n=421).

What was helpful?	What was needed?
Very simple instructions on how to use the platform	Timely provision of laptops or tablets, with appropriate software and follow-ups by IT team
Availability of support over phone or email	Paper copies of schoolwork appropriate to child's needs
	Easier routes to access online learning content
Using the internet to find guidance on how to use new platforms	More focus on the needs of disabled children in design and plan of schoolwork
A parent or family member with tech ability	An alternative for supportive therapies usually accessed through school
Online support sessions with other parents and carers	Assessment of communication needs and provision of necessary extra equipment
Short 1-2-1 sessions with known teachers or teaching assistants	
Signposting of good accessible resources	
Parent training on devices and accessibility	
"Someone to help in simple terms - not all tech speak!"	"We needed more interaction with teachers, other staff and most importantly classmates."
"As a parent, for me to be shown how to help my child."	"We need consistent broadband!"
"I have another child who could teach me, so I could help her brother."	"Thinking about the technology and adaptations used in school and if the same is available at home. There's no point providing a device if the keyboard they use isn't provided as well."

Part 4. Exploring Digital Experiences

This section reports on conversations held with service-providers and parents, and a focus group held with young people. These findings build on the previous section to provide detail of barriers and facilitators to digital inclusion, experienced by families and young people during the Covid-19 pandemic.

Digital disadvantage as experienced by children, young people, and families living with disability during the pandemic is described in terms of:

> → *technical aspects: hardware, software and connectivity*
> → *personal aspects: ability, capacity and confidence*
> → *environmental aspects: relationships, wellbeing and practicalities at home*
> → *consequences of digital disadvantage for education, social support, access to essential information and personal independence.*

Technical Aspects

Hardware

Accessing digital services and schooling during the pandemic required good quality devices in a sufficient number for the entire household. Many people were using phones, or perhaps a small tablet. This can function okay for joining a video call that someone else has set up, but it impacts on outcomes by limiting social interaction – there's fewer people visible on the screen, it is harder to see or use the chat box, and it can be tricky to maintain the webcam at an ideal angle. Parents using their smart phone to join a video call teaching early-year skills found it near impossible to hold the phone at the same time as their child, in order to try out new techniques. Service-providers and educators were not necessarily aware that device availability was limited in the household, and rarely designed their services with small screen sizes in mind.

People using a small screen or with low digital familiarity were disadvantaged during interactions that required the viewing of other files or platforms at the same time as a video call. Assuming that service-users can access and view electronic documents during a video call is not appropriate. Printing the materials could have been helpful in these instances, but also costly. An additional consideration is the need for specialist accessibility equipment, requiring knowledge of these devices, access to them, and understanding of how they are used. For example, children using eye gaze trackers in school may not have had the same equipment at home, and even if the families were given the equipment, their parents may not have had the training and skills for use. Although many people found themselves purchasing extra equipment, such as headsets or webcams, the high demand led to supply disruption with the potential for long delays.

There was a range of initiatives providing technical hardware, aiming to foster digital inclusion by enabling access to video content and communication apps. Additional devices provided by support schemes or through technology loans were not necessarily of high quality, and some of these initiatives were paused when staff were furloughed. Unfortunately, providing these devices did not ensure that the device was suitable for the needs of the person, that functionality was appropriate for the tasks the person wanted to fulfil, or that the necessary skills and confidence were present. The use of devices may have been further limited by connectivity and accessibility challenges. There is a risk of device abandonment if hardware is provided without appropriate assessment, initial support, and ongoing guidance.

Software

Families were having to negotiate multiple platforms across different service-providers and social functions. Setting up new software and additional equipment can feel daunting, requiring a certain level of confidence and time to troubleshoot. Software and online materials created by IT professionals are rarely designed with the needs of

novice or disabled users in mind – there is a need for straightforward technical support, ideally delivered by people with an understanding of disability needs as well as IT.

Individuals might not feel knowledgeable in navigating unfamiliar platforms and programmes. They may have concerns for security and privacy since these aspects differ between different systems. Some devices require credit card details to be stored (e.g. iPads), putting users at risk of financial manipulation and adding to the protective concerns of parents. Although there may be risks with giving out devices without any security parameters, some of the devices provided by (for example) schools were pre-configured to block certain websites without administrative permissions for the user. In some cases, this meant that schoolwork couldn't be downloaded, and families had the impression they weren't being trusted to use 'fun' websites such as Facebook.

Parents and young people might be regular users of some social media channels, but this does not ensure their familiarity with all the possible functions and actions, or that they are comfortable joining a video call or using a new programme. Competence and expertise with software are not simple categories – instead, they could be described as a spectrum ranging from those who are able to join passively as an audience member or consumer, those who are comfortable contributing and engaging with activities, and those who are active in leading activities and mastering additional functions. Supportive services could help develop user confidence by encouraging more active involvement and contribution to digital activities.

Additional functions such as polls or quizzes can be surprising and therefore threatening to inexperienced users, particularly when people are stressed and experiencing limited capacity for frustration. Switching between platforms is demanding even for experienced users. Service-providers can aim to reduce intimidation of new software by keeping things simple, emphasising informality, and allowing time to resolve technical difficulties. 'High whizz' versions of digital services can also be troublesome because they place an additional drain on bandwidth or data.

Connectivity

High-quality internet connection is not consistent – many people with financial constraints use capped data plans, and the availability of reliable broadband is regionally variable. Families and young people that benefitted from free Wi-Fi in public spaces before the pandemic will have had to adapt when the libraries and cafés that they relied on were forced to close. Using a mobile phone data package can be costly, and those with a capped data allowance are limited on what they can participate in, leading to a rationing of digital services because video requires so much data. Setting up with a new internet provider usually involves extra fees and may have been difficult during lockdown, disadvantaging those who had recently moved home, as well as habitual users of public Wi-Fi.

Only the highest quality internet connection can handle multiple people on a video call at once. Access to reliable broadband is limited in rural areas and at a premium in

high-density urban areas. There may have been less technology use in households with low connectivity, before the pandemic, meaning lower skills and confidence in use during lockdown, and perhaps fewer devices. The demand for internet in some households impacts on the potential for engagement with digital services - this challenges interpersonal relationships within a household when people have to work around each other's schedules.

Poor connectivity makes digital group dynamics especially difficult to manage during a call. Multiple people participating in video calls leads to patchy conversations, with individuals left to fill in the gaps and confusion about when to speak. This adds stress for participating individuals who do not benefit from the interaction as they would have otherwise. A person who drops out suddenly from a supportive interaction might have been upset and distressed by the call, or just disrupted by their internet connection – in some services this is a safeguarding concern, and it is necessary for the service-provider to address this with a follow-up phone call. Therefore, poor connectivity can impact the attendance, engagement, and outcomes of digital services.

Personal Aspects

Ability

Disability-related barriers to using technology include physical impairments, particularly around dexterity to safely hold a device and interact with a screen, and sensory impairments, especially poor vision which substantially impacts digital experiences. Other reported limitations on ability were related to cognitive impairments affecting intellectual ability, concentration, and comprehension, and the inability to engage with screen activities due to epilepsy or blue light sensitivity. Social impairments associated with autism can impact on the digital experiences, particularly in a group setting when 'usual' in-person social cues are missing.

Children and young people who can't physically use the technology or need significant adaptations had to rely on parents and other supportive relationships to engage with the screen. This limits their ability to express agency during digital interactions and changes the outcomes experienced. For example, having to interact with friends through a parent might not be experienced as a friendship-based fun activity. The necessity of input from others means that digital inclusion relies on aspects of the interpersonal context that are beyond the control of service-providers.

Additional cognitive load related to digital interactions includes comprehension of the interface and understanding of digital etiquette. Anxiety can be caused by unfamiliar social norms and expectations of decorum, being surprised by screen sharing or unanticipated behaviour of other people, attempting to comprehend content in the context of connection difficulties, and being overwhelmed by the use of additional functions. For many children, but especially those with autism, the loss of routine and essential support was detrimental, leading to declines in mental health and decreasing

ability to tolerate frustration or ambiguity. Distressing digital experiences might result in rejection of digital by the child. Vulnerability to safeguarding concerns might lead to protective refusal by the parent.

Capacity

Unlike ability, capacity changes between days and between tasks. A large amount of time spent online or in front of a screen can lead to fatigue, headaches and physical discomfort. Capacity for fun online and wellbeing activities has been a particular issue during home schooling. It can be more tiring to follow captions when viewing content, or to comprehend class objectives in the context of poor internet. This means that the challenges of completing several hours of lessons each day are disproportionately higher for some pupils than others. When school is digital, and sub-optimal in terms of accessibility and interaction, there may be reduced motivation to engage with additional digital 'fun'.

Managing multiple digital commitments requires an understanding of time and skills in scheduling. There were reports of digital overload as families and young people attempted to filter what was, at times, an overwhelming variety of offerings. In contrast, others found a paucity in the availability of suitable digital content that catered for the appropriate age range and disability needs, despite their best efforts. Searching for suitable options and filtering what was relevant was an additional drain on time and energy that usually fell to parents.

Individuals need motivation to engage with digital, despite the potential for frustration or unexpected experiences; and this motivation requires a certain level of mental health. Fatigue, pain, and personal impairment interact to reduce motivation and thus capacity for digital engagement. Overall, disruption during Covid-19 could be a threat to wellbeing, in that people experienced an interruption to support, a loss of physical activity and social interaction, with impacts to mental health and physical health.

Confidence

Confidence was related to familiarity with technology, previous digital experiences, and comfort on camera, as well as understanding of digital etiquette. Of note is that people may lack confidence in their ability to respond appropriately if something unexpected happens, or the perseverance to troubleshoot technical difficulties. These concerns can add to the anxiety of their digital engagement, making pop-up ads and unexpected functions an additional stressor.

Self-consciousness about being on camera can lead to personal anxiety. Choosing to keep webcam off during a video interaction might reflect concerns about connectivity or the privacy of other family members. However, it may also indicate the person to be uncomfortable on camera in that situation, feeling unwilling to show themselves, or reveal their immediate surroundings. It is unusual to be presented with a live image of oneself, which can be upsetting for those with low cognitive capacity or difficulties with

body image. Parents describe being self-conscious of their 'mum uniform' - looking unkempt, despite having constant childcare and home-schooling responsibilities.

During the pandemic, both staff and service-users experienced intrusion into their homes via videocall. Many people experience worry about being judged on their own appearance or the appearance of their homes, and these worries may be heightened when interacting with professionals. Some families may have felt anxiety due to comparing their homes to those of politicians and celebrities seen on television or felt they were being 'spied on' when professionals asked them to turn on their cameras. Note that blurring the background in a video call is a skill that not everyone has - this produces disadvantage in the experiences of different people using the same piece of software.

Meeting professionals for the first time can be especially daunting, warranting introductory phone calls or photographic 'about me' information beforehand. There may be confidentiality concerns during sensitive conversations, with privacy not guaranteed in the home environment, and the discretion of professionals uncertain from a user perspective. Building trust is a gradual process that is related to interpersonal relationships as well as platform familiarity. Families, children and young people who withdraw from digital services due to confidence issues end up with minimal face-to-face contact and fewer relationship-building opportunities, which could reinforce a cycle of social avoidance.

Being at Home during Covid-19

Family Relationships

The parent (or other caregiver) has an important role in enabling or restraining the child or young person's use of technology. The age, education and professional experiences of the parents influence their skills and confidence in using digital, which then shapes the opportunities of the child or young person. Sessions need a variable amount of parent support - depending on the activity and the child's ability, this might be just to open the platform initially, to supervise throughout the activity, or to provide constant facilitation for their child. In contrast to many in-person sessions, which offer parents respite and peace of mind, digital sessions require the parent's willingness, perseverance and time.

Digital engagement requires active input (or at least permission) from support relationships, so the caregiver could be acting as a helpful assistant or a restrictive gatekeeper, or both, in different households and for different activities. In the pandemic context, parents time may have been a particularly scarce resource for some families. School and supportive services were changed or cancelled, putting extra pressure on parents to provide education and technology support and adding to the burden of caregiving. However, picking up new digital competencies requires time-investment that may not have been possible while multitasking childcare. The presence of 'tech-

savvy' siblings may offset any reticence on behalf of the parent. There were also examples in which disabled young people had coached their parents in the use of digital, for example to access online banking.

Parents without professional experience of internet security may not be aware that they can set up protective controls on the home network, reinforcing any concerns they have that their child needs to be supervised online. Parental safeguarding worries, perceived vulnerability of the child or young person, or a history of online abuse can ultimately curtail future opportunities to develop digital confidence. However, parent expectations of their child's ability to use technology can be challenged and changed. Children and young people can develop new skills and engage in unexpected ways with digital services that manage to harness the power of interpersonal connection. Digital accessibility (or perception of accessibility) is a barrier to this process – but service-providers with existing family relationships are in a position to 'bang on the door' of parents thinking 'this won't work'.

Space and Privacy

There are practical considerations to the home environment that are relevant to understanding the digital experiences of children, young people, and families during the pandemic. Prominently, there are limitations to space and privacy within the home, which can interfere with experiences of digital engagement and family dynamics.

Children and young people may not have an appropriate setting in their homes to find privacy during digital interactions. Although digital services could be offering valuable emotional support or even cathartic entertainment, it can be challenging to find the time and quiet space to join in. Individuals may find it uncomfortable to participate in therapeutic disclosures if they worry about being overheard by other family members. This can mean that people are not expressing themselves emotionally within service – they are constrained by their environment, and not able to fully benefit from the service.

Challenges also relate to noise in the home, with multiple people working and studying, and possibly overcrowded housing or loud neighbours. Individuals may find their digital experiences disrupted by this noise, or instead be conscious of creating too much noise themselves. For example, young people might share a bedroom with siblings and worry about being teased for what they are doing. Freedom from being overheard is important for confidence, especially if using voice to type technology or attempting a new activity.

Parents especially may not have time to talk, being pulled away by young children moving around, or interrupted by other family members. It can be frustrating and potentially embarrassing to have digital experiences frequently interrupted. The knowledge that some of the family struggle to understand which online activities can be readily paused, and which cannot, may become a barrier to motivation.

The necessity of space and privacy for outcomes from some digital services has implications for remote mental health support and social work interventions in the future. This means that the security and density of someone's housing could limit the acceptability and effectiveness of digital support and other services. This is an issue worthy of further investigation.

Threats to Wellbeing

Supportive relationships have an important role to play in creating the social context of technology use for children and young people during the pandemic. However, the pandemic and its associated disruption has led to identifiable threats to wellbeing. Poor or fluctuating wellbeing may impede the ability of individuals to provide support and influence the experience of support for all parties. Everyone in the household was suddenly asked to stay at home, with increasing stress and altered coping resources. Reduced wellbeing may have been related to the loss of routine and suspension of many support services, no external childcare, lack of exercise and little opportunity to see friends or wider family members. The process of accessing food, essential supplies and reliable health information rapidly became highly stressful.

Parents were coping with managing complex care needs and sudden demands to support home-learning – they were under extra pressure as they tried to replace professional input, reporting they have nobody to ask questions to and were mostly left on their own. Families may have been fearful of infection, be infected with and recovering from Covid-19 or coping with the illness and loss of other people. Additionally, there may also have been fear of being judged or excluded when out in public if (for example) the child is unable to comprehend social distancing rules.

These threats to wellbeing paint a picture of growing frustration and stress within the home environment. Everyone could be experiencing increased anxiety and spending more time together without outside help. Challenging behaviour is more likely, with the child's routine taken away and a huge amount of support lost. The more children present, and the greater the extent of medical complexity, the higher the risk of unmet emotional and other support needs. Multiple children also increased the digital demands placed on families, as they attempt to navigate different platforms used by different schools and support providers.

Financial difficulties and digital disadvantage are often overlapping. There may have been more money worries or threats to job security during the pandemic. These apprehensions create extra pressure for professional performance, despite working from home with potentially unsuitable equipment and insufficient internet. Some families, but certainly not all, were able to upgrade their internet package and invest in extra equipment for home use during lockdown. Some families may have been stuck in a situation in which obtaining benefits and statutory support required access to the internet, but sources of free Wi-Fi were unavailable and job centres were closed. These stressful experiences will compound and aggravate other stressors.

The experience and wellbeing of siblings is another important consideration. The pandemic, shielding and the suspension of support services will have had a drastic impact on their lives which could easily be overlooked. Going to school, afterschool clubs, and recreational activities was their 'me' time, which was lost. Their parents, in having to provide more care, became less available to respond to their needs, and siblings may have taken on some care or domestic tasks themselves. Siblings were also suddenly learning at home, experiencing the challenges of inadequate distance learning provision and potentially the stress of ambiguous assessment processes. Additionally, there is the burden of fear that they might become infected and pass on the virus to their unwell sibling or overwhelmed parent. Some siblings may have been at risk of self-harm or abuse of a more vulnerable family member. Increasing mental distress and undesirable behaviour could occur in anyone in the household, struggling with the anxiety and pressure of the situation.

Living with fear and inadequate social contact is highly stressful. These threats to wellbeing during the crisis could have marked and long-term effects on mental health, behaviour and physical health. Recognising these threats to wellbeing and actively supporting each person, including siblings, could help the whole family to cope with a situation of ongoing uncertainty.

Consequences of Digital Disadvantage

Digital services can have a positive impact on mental health and wellbeing; especially when digital enables access to necessary information, encourages connections to other people, and elicits a sense of belonging. A person's environment interacts with their individual ability and capacity, creating barriers or enablers to digital interactions. The reason to use the technology shapes the experience and its outcomes. In-home support to use digital technology becomes highly significant when access to other support from outside of the home is unavailable. Digital disadvantage is therefore related to the task and the situation, as well as the individual. Digital disadvantage could have negative consequences for a person's access to education, social support, information and independence.

Consequences of digital disadvantage could be a widening gap in educational inclusion and attainment. Pupils at home without the right support for education, including digital support and internet access, may have found that their grades have dropped, stress levels increased and social experience decreased. Distribution of devices by schools did not offset high demands for data or internet connection. Furthermore, young people and families reported significant delays in receiving devices or found that the 'safety' restrictions pre-programmed in limited their usability. Lack of sufficient digital resources and space to study at home was a significant challenge for families causing distress for some children and young people.

Children, young people and their parents can experience high levels of stress when presented with barriers to doing their necessary schoolwork. Some children had

inaccessible schooling. Both pupils and teachers were lacking accessibility equipment at home which they had in school, so that work was sometimes in an unsuitable format, particularly for those with visual impairment. Extra notetaking or time for comprehension of standardised lessons puts an extra time burden on pupils with cognitive impairment and a disproportionate pressure on their parents who were trying to support them. Undertaking five or six hours of screen lessons a day is unlikely to be healthy for any pupil, but it was unacceptably strenuous for some.

A negative experience of digital schooling can be indirectly damaging to other digital endeavours because the device or digital interaction is subsequently associated with frustration and other negative emotions. Stress responses from a negative digital experience could mean that the person is less able to engage with other activities, and more likely to avoid similar experiences in the future. Frustration at the personal and interpersonal level is heightened, adding to any other sources of stress in the immediate context. This can lead to a vicious cycle as the person or family becomes more stressed at being unable to achieve their goals.

Facing chronic stress and lingering uncertainty, some children have had low motivation and more difficulties with mental health. Worries about contact with the outside world and social anxiety can become self-enforcing through rumination and lack of opportunity for emotional support. Although siblings can sometimes be sources of age-appropriate coping strategies, there could have been increased pressures in the home environment with children competing for attention and care needs. Parents might be struggling with exhaustion in the current context, and fear or worry about the future. Families may also be vulnerable to increased separation anxiety after so long together without other people.

Digital inclusion and participation can enable self-expression and personal development. Teenagers and young people who are digitally disadvantaged have not been able to benefit from these opportunities, which may have been particularly relevant during pandemic restrictions when there were wide-ranging limitations on independence and activities outside the home. People who might have become more disadvantaged are young adults in supported living settings, that may have attended activities in person but weren't able to access them through digital means. Supportive persons vary in these settings, so there isn't always someone present to assist. Staff can be inconsistent in their approach to digital, and their time and confidence to use it. For example, finding and entering passwords for Zoom can become a hurdle, such that there's a need to balance safety and availability during service design.

Digital disadvantage furthers uncertainty and its detrimental impacts on mental health, by decreasing access to accurate information including essential public health information and legal requirements for lockdown restrictions. The rapidly shifting context and changing guidance increases the need for information and consequences of barriers to access. People without access to information have less knowledge of rules and new social expectations, and increased ambiguity about how long the

measures will last. Unfortunately, essential information was not always presented in accessible formats during the pandemic. Government communication (especially) should be considerate of the needs of people with sensory impairment, visual learners, and those with English as a second or other language. Creating formats with key content as simple as possible to comprehend makes it less demanding to access information access for everyone.

Whereas digital inclusion can offer access to social support, which improves coping, people who are digital disadvantaged may experience declines in social support because they are less able to communicate via messaging and video platforms. This makes it more challenging to maintain relationships with friends and family outside the home and may long-term impact the person's motivation to engage with technology. People with disability and high care demands are at greater risk of social isolation than the general population, so digital disadvantage as a barrier to social support could be consequential in increasing the likelihood of further isolation.

Part 5: Service Adaptation during Covid-19

This section reports on service adaptation and innovation during the pandemic towards digital service provision by charitable organisations that support disabled/seriously ill children, young people and their families. In general, there was extensive change in response to the needs of users, meaning that services could provide support and maintain existing relationships. This was instrumental in facilitating information provision, peer support and protecting a space for play, despite the challenges of the pandemic.

Some services supported users to develop their use of digital, which may have had beneficial consequences for their ability to access other sources of support and information, activities for wellbeing and opportunities for personal development. Service adaptation has revealed some of the advantages and limitations of digital and indicated available strategies to encourage digital inclusion. Increased use of digital also changes staff experiences, which is discussed at the end of this section.

Evaluating Sector Response

Services were highly responsive to the sudden lockdown and the changing needs of service-users. In addition, services were receptive to and reflective on feedback they received following a rapid switch to online activities. They might have adjusted the timing and contents of their services - some were able to facilitate more frequent contact and greater flexibility in scheduling. For example, one service moved from monthly structured sessions to bi-weekly chats to address social isolation when schools stopped. Providing a regular session meant that families had something to plan around when other routine had been lost. Others developed an asynchronous offering as resources to be accessed whenever required. Providing choice between services increased their adaptability and suitability to the varied experiences of different families and young people.

Providing some support was vital within the profound disruption of the pandemic, particularly at a time when many families were feeling isolated and abandoned. Although there are concerns over the effectiveness of some digital adaptations compared to face-to-face services, there is clear value to maintaining contact in comparison to the complete loss of support. Adapting to digital services has allowed supportive interactions to be partially maintained and some meetings have been able to progress as much online as in-person. Existing relationships with the service and one-to-one guidance and encouragement from a known service-provider could have empowered some families to engage more with technologically enabled communication than they might have without this additional input. Some families have

declined digital offerings, preferring telephone calls, or opting to wait for the return of in-person support.

Adapting to a digital format can mean reaching a different demographic – some organisations have extended geographical coverage and experienced greatly increased demand. For example, rural families and busy professionals might have been more able to attend activities held online than in person, due to negated demands for travel and for childcare. There is potentially cost and time savings for both parties. Being able to participate from home includes people who find it difficult to leave the house due to medical complexity, mental health, or personal care needs. Furthermore, people lacking confidence to attend in person or experiencing internalised stigma towards disability may feel more comfortable tapping into an online event than attending in-person, particularly if it is their first time engaging with an organisation. Digital services can have added value when it facilitates the inclusion of interpreters and translators. Some services reported more uptake from people in lower socioeconomic groups and certain cultural minorities.

The scale of innovative change has been impressive. Experiences of adaptation have demonstrated the importance of consultation, engagement and communication; both within teams and with service-users. Involving families in the design and evaluation of digital services can allow for continuous improvement. However, with ambitious responsiveness there may be constant change and widening of scope, meaning a risk of staff burnout. There are remaining concerns about how to promote digital offerings outside of existing networks, and especially how to reach digitally disadvantaged individuals when most marketing and communication work occurs online. Evaluating engagement and effectiveness is challenging, and outcomes might be inconsistent because so many contextual factors are influential.

Advantages of Digital

Digital service delivery is not simply a gap-filler – it has its own advantages. In some circumstances digital may be preferred over face-to-face options. However, the needs of specific user groups must be known and considered during service design to avoid digital exclusion and minimise digital's limitations. Depending on the specific people and situations involved, digital can have the following advantages:

- It is usually cheaper for informal get-togethers and events to run online, at least from the service-provider or organiser perspective.
- Practically, digital delivery minimises the need to travel to a meeting location. Not having to travel and negotiate car parks and new buildings can be a substantial positive for people with physical limitations or sensory impairments. It also enables professional involvement.
- Beyond travel, remote participation might relieve social anxiety in group situations, and reduce apprehension around other practicalities such as catering, personal care needs and childcare.

- It can be more straightforward to arrange digital meetings quickly, rather than waiting until in-person meetings are allowed, and a suitable space can be found. Prompt progress can be especially important when responding to developmental challenges which have consequences from delayed intervention or referral.
- In some services, digital delivery can help deepen staff and service-user relationships, through more personal and direct communication compared to a busy in-person group, and an insight into the home environment. Service-users might sometimes be more confident to suggest ideas, explore therapeutic concepts, or try new things from the comfort of their home.
- Digital delivery can enable someone to discreetly attend an activity without having to disclose it to others – this is especially beneficial for people experiencing disapproval of attending in-person, for example due to stigma towards disability.
- Participating regularly in digital services can enable people to feel more knowledgeable and confident in using technology, which could bolster self-esteem and social skills in-person.
- Online confidence and digital skills can transfer to other technology-enabled activities, which may be beneficial for education and employment in the future and contribute to myth-busting on what some people 'can't do'.
- Digital delivery can improve consistency from the child's perspective, by including those that are too unwell to leave their home and creating access to supportive activities, learning and entertainment during hospital stays.
- Digital delivery removes geographical limitations, which can enable age-appropriate social interactions with peers that have similar personal interests, health conditions, or physical and sensory experiences.
- Finally, pre-recorded content or automated digital services removes time limitations, so that benefits for fun, information, or connection can be accessed any time of the day.

Limitations of Digital

The advantages described above are not guaranteed. So many factors of the home environment are influential to the digital experience and its outcomes and are usually beyond the control of the service-provider. However, some limitations of digital service delivery can be reduced through thoughtful service design that considers the needs of the people involved. Digital service delivery can have the following limitations:

- Interpersonal communication through digital has different qualities to in-person communication. The information we usually gather in-person, through body language and group dynamics, contribute to social feelings of connection, safety and belonging. It can be much more difficult to foster a new relationship when interacting through a screen because non-verbal communication is lost or highly altered.

- The quality of interpersonal connection can be impacted by the available digital infrastructure, rather than the people involved. For example, the tone of voice and facial expressions are not fully conveyed through a video call and this is especially so when the connection is sub-optimal.

- For most people, interacting with a screen is not as stimulating or as motivating as face-to-face socialising. Children can find these interactions more draining, partly because it is harder to concentrate on what is happening, or they might not comprehend that there is a person on the other side of the screen. Service-providers and parents can feel less convinced of the benefits of a remote activity.

- Touch or physical interaction can be a strong feature of the support received by individuals with complex needs or sensory impairment – it is much more challenging and time-consuming to build connection while 'disembodied'.

- Engagement with the screen is necessary, and this might not always be possible within a person's independent ability, creating additional demands for parents or caregivers. Early years diagnosis and intervention is especially difficult over a digital interaction.

- People have different digital needs that can be difficult to predict. It is necessary to adjust expectations and seek to identify and address in advance any digital barriers. This can add complexity to the planning process.

- There are benefits to face-to-face services that do not transfer to digital delivery. In a group setting, attendees can more easily form friendships. These peer connections emerge as sustainable sources of support outside of the service that helps to embed its outcomes. Achieving these friendships from an online group is much more challenging.

- Some in-person services that focus on the child or young person also create respite for the parent, or 'me-time' for the sibling. Where digital services demand input from supportive persons, that means more tasks for the household to juggle, without respite.

- The device itself may be associated with school or work. Challenges experienced in one digital interaction can mean transferred anxiety or frustration to other activities using the same device.

- Getting out of the house can be of benefit from in-person activities, but this is not a feature of the experience of digital services. There is an additional issue of screen fatigue, even during positive interactions – although it differs between people, there is a limit on how much screen interaction one person can manage.

- Finally, services are often designed by people using laptops, tablets, or desktop computers. Service-users are often using their phones. Professionals accustomed to daily use of digital can be unaware of the complexity involved in (for example) using the chat box or opening separate documents on the small screen of a smartphone. They are therefore less able to advise people who are unfamiliar with the platform's functionality.

Table 3: Adapting to digital – overview of strengths and limitations of digital delivery

Strengths and advantages	Limitations and barriers
Speed of adaptation	Families lacking confidence, equipment, or connectivity
Responsiveness to feedback	Supportive persons have extra responsibility and lose respite function, reduced down-time
Digital is cost and time-saving	Invasiveness to home environment
Removes geographical limitations	Concerns on reach and depth
Participating from home or from hospital can improve accessibility for some	Big change for staff: their work might feel less hands-on and less rewarding
Can be more focused interactions	Challenge to design engaging activities

Strategies for Inclusion

Phone Calls

• Using familiar technology
• Emotional support & information in the crisis
• Guidance in how to use digital platform

Tailoring Content

• Knowing the needs and interests of service-users
• Seeking & integrating feedback into practice
• Adaptations to help information processing of different learning styles

Remaining Barriers

• Evaluating engagement
• Maintaining staff wellbeing
• Reaching priority groups

Tech-Savvy Staff

• Support to get to the digital space
• Knowledge of possibilities e.g. for equipment
• Creating a relaxed online setting

Physical Components

• Keeping contact with doorstep drop-offs
• Materiality and sensory contact enable connection
• Making an activity more active and a group feel more real
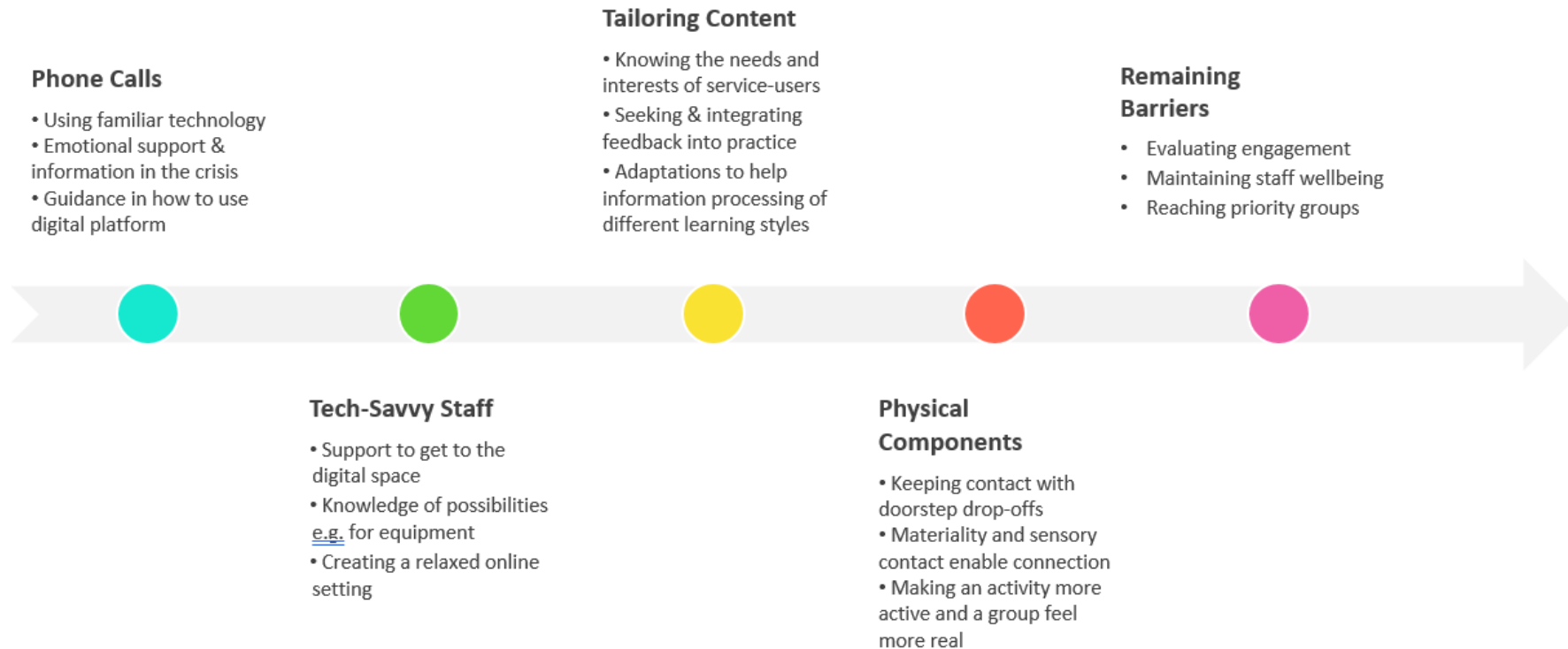
Figure 1: Strategies for digital inclusion described by service-providers during digital adaptation in the Covid-19 pandemic

A Process of Learning

An important first step is to understand technology-based challenges as a process of learning, rather than a block to digital engagement. People need support, and sometimes hands-on input, for them to gain familiarity with the interface and build confidence they'll be able to respond if something unexpected happens. It is beneficial if the support is provided by a known person, with an existing relationship and understanding of individual needs, in contrast to an anonymous IT professional who may not know the person's abilities, preferences, and personal strengths.

Particularly for new services or at the beginning of a group, recognition that everyone is learning together can help to relieve anxiety that something will go wrong. It is valuable when staff can identify multiple options to overcome challenges, allowing families and young people to choose the route they most prefer. Staff enthusiasm and knowledge is key to supporting this process.

Using Phone Calls and Texts

When service-users are being introduced to a digital service, for example before joining a Zoom training group, it can be useful to have some communication beforehand. This contact helps to encourage service-users' participation by providing a one-to-one opportunity to explore sources of worry and identify potential technical challenges. Some reluctance towards new technology can be addressed over the phone, particularly if the service-providers have sufficient confidence in the platform to guide new users through the first use.

During the pandemic, phone calls were useful to fill in the gaps between services at times of disruption and uncertainty. Texts were also useful, as reminders of upcoming events or as simple check-ins (e.g. "we're here if you need us"). Staff might also produce written 'how to' guides for parents or young people, including common aspects of troubleshooting, and advise on extra equipment such as headphones. Staff intervening proactively to give this support requires their time and for them to feel supported to do so by management.

"Oh the joys of a phone call when everything else is online."

Tailoring Content

Specific programmes can be tailored to the needs of those attending. Through digital, it can be harder to get to know people in the same way as face-to-face, and much trickier to get immediate feedback and engagement from the group. This can create challenges for person-centred content. However, the practice of holistic initial assessment conversations can start to build service-provider's understanding of the situation and connection with the service-user. Examples in which entertainment or fun activities were tailored to the personal interests of the child seemed to benefit their engagement. Music can be particularly engaging, using familiar songs and including

the names of children attending. Furthermore, when children were able to contribute their own ideas, they gained an opportunity to think through what they wanted and express their preferences.

Recognising that people process information in different ways and at different speeds, and that additional time for processing content may be needed, some services developed visual stimuli or prompts for engaging – e.g. PowerPoints with live edits so that service-users could see their input happening, or the wearing of green t-shirts as a cue for fun. Service-designers might reflect on what can be done in terms of pre-event communication to gain insight into what adaptations could be most valuable. Tailoring content can also mean offering a balance of services, for example, a mixture of regular scheduled activities and informal drop-in type options. This mixture can meet the varying needs of families (not just between households but from day-to-day) by providing some activities to structure the day around, and other support that can be tapped into when needed, without the pressure to turn up and be on time.

Physical Components

Using physical components or props adds an element of touch and materiality that extends the activity 'out of screen' and makes it more 'real' for service-users. Examples were hard-copy workbooks or activity packs. Providing these resources as something to interact with in between sessions gives something to discuss in the session. Activities and 'real-world' challenges can extend engagement beyond the time defined by the video call. Furthermore, physical components are an opportunity to take suggestions from service-users and experiment with new ideas, inviting them into the planning process and encouraging choice and agency in choosing the activity.

Physical components enable conversation, but since they also represent the 'doing' of something together, they facilitate a reciprocal connection that might create a sense of group belonging and companionship, even via remote communication. Physical components can also develop into a therapeutic activity for (e.g.) the child and parent interacting together with something new, facilitated by the screen but not restricted to it.

Remaining Barriers

Despite the above strategies, there are remaining barriers to benefit. These require specific consideration and co-produced responses. It is not well-understood what digital skills are missing as a nation, and we lack multi-cultural understandings of where the digital world is not embraced. While the right to decline digital should be protected and respected, addressing digital disadvantage is about offering choice, so that families who want access to digital are able to do so. In some cases, low wellbeing within the home will be the main barrier to learning, such that organisations might wish to focus on (for example) emotional or financial support for parents, facilitating conversations within the home around digital use, taking a 'wellbeing-first' approach.

To alleviate digital disadvantage, universal design needs to be more widespread across society. This would mean creating content that is suitable for everyone, rather than creating a separate offering suitable for the people that have been excluded by an inaccessible design. Therefore, questions can be asked on what needs to change for accessibility to be a key component in the development of all digital services, rather than an afterthought.

Initiatives attempting to address digital disadvantage should consider the reach and depth of interventions. Referrals from healthcare professions and local statutory services have been intermittent during the pandemic, but even in full operation these systems still have gaps in reach. Charities and third sector organisations can build network links with schemes providing technology loans and free Wi-Fi provision, but barriers can go beyond technology. Reaching digitally excluded groups requires proactive communication strategies, cultural sensitivity, and an awareness of varied English language literacy – not just the provision of devices. Some organisations have been creating events to showcase digital opportunities and encourage long-term cultural change towards technology (examples are with families from Roma, Orthodox Jewish, Muslim or Eastern European backgrounds). Such interventions would ideally be co-designed by people with lived experience to be culturally sensitive of barriers experienced by different groups of people, such as expectations of gender and parenting roles.

Evaluating engagement with digital services and the outcomes of interventions towards digital inclusion is another challenge. Interventions need to have clearly articulated goals and an understanding of how these might be measured. There is a remaining issue of how to target content to people who are digitally disadvantaged, when most marketing and communication strategies are online. Finally, an additional factor during digital innovations is to consider the wellbeing and skillset of staff – limited experience and low confidence working with technology can be a barrier to successful digital service provision. There are challenges involved in adapting to digital and working remotely, which are explored in the next section.

Needs of the Workforce

"Am I working from home or am I living at work?"

Staff members with experience in and enthusiasm for the face-to-face support of children, young people and families rapidly adapted to other means of supportive interactions. Changing the format demanded different skills, which were supported with added training. Some professionals benefitted, especially from the improved flexibility and reduced travel demands. However, in some cases they were uncomfortable delivering digitally. This was related to lacking confidence or ability in using the technology, lacking necessary equipment and connectivity at home (at least initially), and changes to the rewarding aspects of the job itself. Losing access to a

collective office space, having less down time between work interactions, and increasing time-demands for the job could also be relevant factors.

Offering support at a distance, whether over the phone or via a video call, was a new challenge. Some staff roles had previously been characterised by hands-on work with children, in group sessions, and face-to-face with family. When other work tasks are screen-based, they had looked forward to the interaction with service-receivers - their energising engagement and feedback was not guaranteed in the switch to digital. Typical strategies to engage with disabled children and young people may not be effective via a screen and it is much more difficult to facilitate a balanced conversation within a group. It is much harder to 'read the room' in a group videocall - especially when cameras are off - but even with webcams in use, there are cues from body language and facial expressions that do not transfer. From the staff perspective, it can be incredibly draining to lead a session (e.g. 90 minutes) stuck on a screen and 'performing into a void'. This could be made easier when other staff members were virtually present – they might be pitching in with their own energy and ideas, or available to debrief afterwards.

Staff members had to gain confidence with using the technology and being on camera themselves. Individuals that had not been required to use such platforms in their professional or personal life before were asked to rapidly upskill at the same time as supporting service-receivers to engage in new ways. Connectivity is not sufficient in rural areas, so that some staff were more likely to experience technical glitches such as the video freezing. These interruptions exaggerate the communication difficulties of digital connection, because some parts of the conversation are lost and or made more difficult. Staff may have had to upgrade their internet package and invest in home office equipment during lockdown, which is more of a challenge for people on low wages, part-time hours, or short-term contracts.

Some staff readily adopted digital delivery, seeing the benefit of maintaining support even through strict lockdown measures and enjoying increased flexibility during their working day. Staff might have experienced some challenges when working from home in managing the boundaries of familiarity as well as time. Some staff may have felt that they needed to be more available for work tasks outside of their usual hours. They described experiences of technology invading their homes and family life, especially at times when all family members were working or studying remotely. There were concerns about bedrooms and private spaces being on camera. Knowing what is appropriate to share and what isn't becomes trickier when all interpersonal interactions are via the same screen. Clear communication from leadership, articulated expectations regarding working hours and opportunities to discuss challenges may help to build trust and willingness from these individuals.

Giving emotional support during times of high uncertainty can be personally exhausting and time-consuming. Particularly during the initial crisis, work demands increased at the same time as disruption affecting their own households. The

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workforce may have been operating across multiple digital platforms for their social and professional lives, each with their own interface and security implications (i.e. Zoom, Teams, NHS platforms, email inboxes and Whatsapp). Training had to be given and generally seemed to be appreciated where it was received. However, identifying and participating in extra training can be less of a priority for individuals who are managing the needs of their own family whilst also responding to other families in distress. Those who took up the training seemed to be those who were more engaged with digital delivery – extending the invite and appeal of training is more challenging.

Digital working can lead to some improvements in productivity, but there is a social cost, because staff lost the creative and supportive space of an in-person office. A team office space represents a pool of knowledge that enables signposting and informal emotional support. Working remotely means it is much harder to casually ask questions, so fewer questions get asked. The restorative 'team cuppa' was lost, such that staff may have felt less supported to do their job, and less effective in providing informational support to service-receivers. In instances where working practices were paper-based previously, shifting to digital within the workplace has enabled some aspects of team working, and it was viewed as an achievement to remove the 'safety blanket' of paperwork.

The social context of working matters, even at a distance. The needs of the workforce and the uptake of training can be influenced by how much the individuals feel a part of the organisations they work for. Teams benefitted from virtual opportunities for face-to-face communication and reflection on challenges experienced. Examples were regular supervision, informal check-ins and collaborating when developing resources. The behaviours of people in leadership roles sets a precedent for the behaviours of others, particularly around use of technology. Peer-level staff that are 'tech-positive' can provide personalised guidance to colleagues.

Many people are more able to cope with frustration in a collective setting than they are at an individual level, so upskilling staff who are not currently engaging in digital training may require opportunities to learn in an in-person group setting. Beyond the initial adaptation to digital, it is important to continue with opportunities for training and tech help, including informal approaches to skills development such as drop-in sessions and peer support.

There is a need for balance between empowering people to find new ways of delivering and achieving consistency in what is being delivered. For example, there can be confusion about security and privacy across different digital platforms, but top-down rules conveyed by management can prevent practitioners from tailoring their work to the preferences of the family. Understanding feedback and continuing to integrate this into practice could be important for staff who feel distanced from the outcomes of their work. A structure for reporting feedback might also increase communication between staff and leadership, contributing to a sense of belonging within the organisation.

Questions remain on evaluating engagement and the best way to involve users in the development and launch of services.

The digital journey of the service-provider converges with that of the service-user; and this process is shaped by previous experiences and existing relationships. Staff intervening proactively to give digital support requires motivation, perseverance and permission to do so – practitioners embracing technology and being willing to try new things can be picked up on by children, young people and parents. Therefore, digitisation relies on staff enthusiasm in order to overcome challenges and scepticism. There is risk of a widening gap between staff that do and do not feel comfortable in delivering digital. It is of utmost importance to bring people along with the changes so that staff know how to use the technology to support and improve their work, rather than seeing it as a barrier between them and the service-user. This analysis suggests an emerging and problematic gap in the work force: where professionals with knowledge of IT operate separately to professionals with accessibility and disability knowledge.

Change towards digital reflects a cultural change within an organisation as individuals learn new skills and adapt their daily practice. Digital workplaces can have advantageous flexibility, but technology-related stress can be problematic. The importance of social spaces for informal communication and supportive learning is not passively transferred into digital spaces (Hult & Bystrom, 2021). Recommendations from published literature convey the need for consultation prior to roll-out, minimal added complexity and clearly communicated expectations (Yates & Lockley, 2020; Mazmanian, Orlikowski & Yates, 2013). Elaborating on the needs of the work force in digitisation indicates the value of organisations being proactive in ensuring digital competence and staff wellbeing during the process.

"People know what they need to know, and no more."

Part 6. Case Studies

KIDS: Early Years Support and Learning Provision

This regional service provides learning and support sessions for 0-5 year olds, usually held in children's centres. Sessions were moved online at the beginning of lockdown, accompanied by weekly phone calls to families. However, the team experienced challenges in working this way – what was a hands-on role with early years children became an emotional support role for parents. Workload increased as one-to-one calls were time-consuming, staff were distanced from the rewarding aspects of supporting a child's development and team members were less in contact with each other.

Accessible Content

Early years children are unlikely to sit nicely with a device and might not recognise or engage with staff over a screen, even if they have met the adult before in person. Parents were interrupted from conversation by being pulled away by the child or other family members requiring attention. Video calls were frequently disrupted by connectivity issues and low attendance led to a high staff ratio that contributed further awkwardness. Many parents opted for phone calls over attending video sessions, at least in part because they were able to move around with the child while speaking on their mobile phone. The expectation to come onto video led to anxiety about their appearance and home environment.

The team learnt that 'live' offerings at a set time created an extra time pressure for these families. A solution was found in pre-recorded content – asynchronous services were advantageous for this age group. Staff members made video content designed for the under 5s with Makaton. Recordings were a short length, working with the attention span of early years children, which meant they were available when needed and could be repeated as desired. Recordings could be downloaded in advance, which meant the entertainment was less vulnerable to connectivity issues. Staff advised on how to download these recordings and screencast them to a television screen.

Including cues for fun in these videos improved child engagement and provided continuity. Examples were wearing staff T-shirts and singing welcome songs, that the child could recognise from face-to-face settings. Activities were based on components used in the settings, on fun that could be had at home and centred around particular child interests – e.g. staff playing with parachutes, telling stories, facilitating scavenger hunts, making videos of themselves baking, and recording their washing machines. Some live sessions were maintained, in which staff might take requests for favourite songs and nursery rhymes. Facilitators emphasised the informality of these sessions, specifically that families could join at any time and leave at any time.

Activity Packs

Providing accessible content for early years children appeared to be valued by families, but some practitioners struggled to work in this way – feeling they were performing into an abyss, with little feedback from children or families. They had hands-on roles previously, but now felt at a distance to the fun and enjoyment they hoped to inspire. Activity packs were a new component that transformed the experience of 'remote' support. These were delivered to the household's doorstep or picked up by families from car parks, allowing for real interaction between staff members and families.

Seeing a face in person was worth so much more than a telephone or video call under lockdown circumstances. Staff who struggled over technology enjoyed taking out activity packs – practitioners found that children recognised them, even while wearing facemasks, much more than they did over a video call. Even a brief and distanced meeting face-to-face with parents was helpful in maintaining or developing a relationship, and staff members reported that parents were much more open and honest with them in subsequent phone calls.

Parents valued the fresh play ideas facilitated through activity packs, after long periods stuck at home, potentially without financial or time resources available to get new toys and find new ways to entertain their child. This is especially relevant for early years children, whose interests and abilities might change markedly from month to month. Activity packs provided something physical for parents and children to interact with together, away from the screens. These were sometimes themed, for example for Easter, Halloween, and Christmas. Afterwards parents might, for example, share a photo of their carved pumpkin. It's possible that these activity packs reinforced a sense that other families were going through similar experiences.

SENSE: Buddy Programme

This national organisation supports children and young people with multisensory impairment and complex needs. Prior to Covid-19, digital was underdeveloped - staff, volunteers, and users were all new to videoconferencing platforms such as Zoom, and even the senior leadership team experienced some initial apprehension. However, the pandemic situation demanded creativity and adaptivity to maintain contact, and so a collection of courageous individuals led a rapid conversion to digital.

Positive Activities

A programme of arts, sports and wellbeing activities began online delivery in April 2020. They were intended to be engaging, high-quality activities that were accessible for a range of ages and abilities. These positive activities were presented as a mixture of live and pre-recorded sessions, with 'low-tech' components as props that went along with the experience. Similar to the activity packs discussed above, including 'low-tech' materials was an important feature of the success of this programme that made all the

difference in changing passive screen consumption to a shared positive activity. Examples were sensory toys, wellbeing packs, quiz or game worksheets and other fun items like glow sticks or jewellery making packs. These components were distributed to families, serving to engage children with the activity and potentially facilitating a sense of connection between families.

The monthly programme was reviewed regularly with input from those attending. Feedback was important for new ideas to emerge and may have also benefitted the staff's experience. Having a regular routine of activities provided some families with the structure they needed to get through these difficult weeks and months. Moving forward, the pre-recorded sessions are building a resource for the future – a library of activities for use by families and service-providers.

Virtual Buddies

The virtual buddies initiative connects disabled children and young people to build a friendship with volunteers. Importantly, buddies are matched based on personal interests, chosen hobbies and preferred methods of communication - rather than age or illness. This means they are matched on the qualities that drive a friendship, rather than a medical record. Due consideration during the matching process helps to create reciprocal support opportunities, valued by both sides. For many volunteers, the virtual buddy was their only new friend from a year of social disruption.

Most buddies use video or phone calls, but some use email or text, with contact at least once a week. The friendship could develop around the structure offered by the positive activities programme. In addition, the buddies gain from expressing agency in choosing what they would like to do and preparing for their activity between the sessions. They developed a partnership through shared planning and decision-making. Activities were supported by physical components provided by the charity, for example popcorn and sweets for movie nights, craft packs for jewellery making, or even hard-copy books to read together and discuss.

In most cases, buddy sessions do need variable amounts of parent support – sometimes just to open the video call platform, but sometimes constant supervision to enable their child to participate. This requires parent willingness and time, in contrast to in-person buddies that offer parent respite when, for example, the buddy takes the person out of the house for an activity. However, parents might still benefit from the regularity of the session, in that it is something they can plan around, providing some routine when other routines have been lost. The charity offered technical support by providing extra devices such as tablets and is now increasing their provision of additional data using MiFi options, recognising that connectivity is often a limitation on video calls.

Siblings and Parents

A sibling programme was a new initiative, introduced to provide support specifically for young carers and siblings. These are online virtual sessions on a monthly timetable, tailored to the personal interests of those involved and suitable for different age groups. These might include physical activity, art, cooking and music. Resource-packs are provided where needed, such as for baking classes or for ten weeks of guitar lessons. Sessions on wellbeing allow siblings to share and explore their role in the family, their feelings in providing car, and the emotions that they experience at home. This could be an important opportunity for managing mental health, not just as the sibling of a disabled person, but also as a young person in the pandemic.

The siblings programme allows for their service-users to come and go, to access the resource when its needed, without committing to a fixed programme. The programme has attracted new contacts, and deepened the support offered to known families. Finding the privacy to participate has been an issue in some cases, but the charity has facilitated conversations so that the sibling can have some time alone to join wellbeing groups.

Parent chats are drop-in, informal sessions allowing parents access to valuable peer support. Adults don't need to commit to attend, which is of benefit when they struggle to predict the needs of their children in advance. They can easily skip it if something comes up but might still benefit from the knowledge there's something available to tap into. Activities include tea and coffee mornings or cocktail hour in the evening. Parents can talk about anything, not just parenting, and have the opportunity to share experiences with people in a similar boat so that hopefully they feel less isolated. Finally, an active Facebook group can be another information-sharing resource and option for social coping, that is convenient to access and available out of hours.

Rainbow Trust: Zoom Play Time

This regional charity supports children aged 0-18 with a serious illness and their families by offering practical and emotional support. A named support worker builds a relationship with a family by visiting the child at home and in hospital, offering transport to medical appointments, providing sibling support and emotional support to all family members. The majority of these families were instructed to shield during the pandemic, with some taking this decision earlier and requesting video call alternatives. Although there was initial reticence from staff and a steep learning curve, pre-existing relationships and team collaboration helped to ease the transition to a digital format.

Keeping the Relationship

Many of the children supported by this charity spend long periods of time in hospital, in relative isolation – for example, before a bone marrow transplant. This means they are familiar with using a tablet device for play and entertainment during stays in hospital. Some had already accessed grants for them to have their own devices. The

child's understanding of video calls was helpful in overcoming language barriers experienced by some families. The first Zoom can be tricky for any family and support workers used text messages and phone calls to guide parents/carers through its use.

Families with multiple children of varying needs might find it hard to leave the house, even when they feel safe to do so. Given their risk of social isolation, it was valuable to keep that hour or two of personalised contact and care from someone outside the family. For the children, adapting the format to digital meant protecting their dedicated time to play, without other distractions, when everyone else at home has their own things going on.

The call could be arranged around the needs of the family, for example during an important work call or medical appointment, so that children are entertained, and interruptions less likely. This can be especially helpful during healthcare appointments when the adults need to concentrate on what is being said and perhaps take a break from active parenting so they can process any new information. Some families did choose to opt out of Zoom calls during school term time, and there were occasionally families that chose not to have WiFi at home, meaning they declined this format entirely.

Parents or caregivers set up the call and might choose to share what's been going on for them with the support worker at the beginning of the conversation – providing an emotional outlet for them, whilst giving the support worker some contextual information on the household. Perceiving the child's fluctuating moods is more challenging through digital, so this initial check-in was valuable. The main focus was on entertaining the child or children, but adults might still be in the background, meaning that they can intervene if there is (for example) squabbles between siblings. Support workers can also offer support to caregivers, providing dedicated time and space to talk about what was going on for them. Furthermore, because the support worker was a familiar person to the whole household, parents and carers might have been more comfortable showing their home and parenting style than they would have been to a stranger.

Support workers were working from home, sometimes from their own bedroom, and had lost the 'down-time' of travel between appointments. This could be challenging, but the charity was proactive in offering regular supportive check-ins, team meetings, monthly supervision and continuing provision of free monthly counselling for staff.

Finding the Magic

"If they weren't talking to me, I could talk to the puppets. The child might then get a toy who would join in the conversation… the magic of wanting to believe is huge."

Achieving screen engagement can be difficult, especially with young children, and there is a risk they become frustrated or distracted. However, the interaction was enabled by the support worker's knowledge of the child's personal interests and favourite toys and by the team's collaboration. The overall approach prioritised playing

with the child - following their lead and seeking their ideas on what to do next – but the support workers also had a team 'cheat sheet' for Zoom activities, shared internally as an ongoing list of ideas to inspire screen fun. Playing with toys such as dolls and puppets was found to be an effective method for drawing in the child's attention. Where the staff member had been in the home before, they knew what toys could be called upon, although these insights could be gained from the caregivers or the child themselves.

In some cases, the puppets themselves became the play partner. For example, interjections from a cheeky imaginary character could crack jokes and diffuse frustration experienced by a five-year-old, who usually found it difficult to take part in video calls. Seeing this familiar fictional 'person' every week, the child developed a confiding relationship in which they explained things which they might not share with adults. This became an emotional outlet in which the child could describe variations in their siblings' health and describe family events from their point of view. For mobile children, scavenger hunts around the home were an effective way for siblings to play together and to communicate about emotions, prompted by the support worker with tasks such as "find something that makes you feel safe."

Other child-centred strategies included shared time using google images with the support worker operating a tablet for the call and showing the child their laptop through that screen. Together they made mind maps from pictures of the child's interests, and the support worker printed and posted this creation to the child. Using technology together, in a remote but relational way, was fun for both sides and was not prevented by limited vision, mobility, or dexterity. In this case, the teenager valued having their own weekly meeting – it made them feel grown up and gave them the opportunity to make their own decisions in leading the content and pace of the activity. The calls gave them someone talk to, independent of the family.

Connection challenges related to poor broadband were experienced by some families, meaning that conversations with adults were breaking up and disrupting two-way chat. Fluctuating internet quality seemed less noticeable or disruptive during child play, at least during some activities, perhaps because the child is so engaged in the fun. Children were encouraged to think through what they wanted to do and often had their own ideas for an activity. The child or teenager's mood and energy might fluctuate due to their health and the effect of treatments, so in some cases they just wanted to watch a movie together and chat about what they had seen that week.

Before the pandemic, if the support worker had a cold or someone at home had a stomach bug, the visit would have been cancelled. Now that the organisation has developed a digital practice, they have an extra option to a face-to-face visit or a missed session. The pandemic has been difficult for many of these families, especially those living with suppressed immunity, but service adaptations made during this time has enabled services to meet family needs more flexibly in the future.

KIDS: Young People's Participation

These groups are for ages 13-25. Volunteers are former beneficiaries and several staff members have lived experience of disability. Before the pandemic, they met on a monthly basis for specific participation activities, such as delivering training for local authorities.

During lockdown, activities changed to respond to the needs of group members. They moved swiftly and successfully to provide and encourage virtual engagement with young people and others. Previously focused in the South-East, moving online removed geographical limitations, so that people were joining from across the country. Going forward, the group will take a blended approach, using conference kits to facilitate digital participation within a face-to-face meeting. This blended approach will enable involvement of people who would otherwise by excluded by the requirement to travel.

"The key principle of participation is that it's a choice. Everything we do is about giving them the choice."

Person-Centred Tech

During the first month of lockdown, group facilitators spent a lot of time on the phone with service-users, offering one-to-one technology support to enable digital group activities. Some technology-based challenges could be overcome with the right advice and input, for example by encouraging the participants to get headphones, and by producing a written simple 'tip sheet' for each platform. It appears beneficial that the facilitators had confidence in this skill set that they could pass on to others, at the same time as having good pre-existing relationships, so could ask the right questions.

Two-way communication meant that lessons could be learnt on specific actions that practitioners can take to enable participation in advance and during the meetings. Providing information, questions or topics in advance of meeting allows for preparation and thinking time – all people need time to process materials, but some people need much longer, so providing materials in advance improves the flow of the session, meaning that conversation happens more easily because people have already had time to think about what they wish to contribute. Visual stimulus is helpful, especially for visual learners and people with concentration difficulties. Physical workbooks can also be an advantage, because it is more flexible for participants to make notes and record thoughts when they come up, before being 'on screen'. The facilitators observed that having something physical has been effective in making the interaction more real and combatting screen fatigue.

Communicating in advance, preparing hard-copy workbooks, and providing person-centred tech support enabled participation in providing evidence for an All Party Parliamentary Group during the pandemic. This was highly valuable because it allowed for their voices to be heard by policy-makers, improved the confidence of

those involved, and provided experience in employability-relevant skills. The sense of achievement from participation increases confidence for the future in that the individuals know they can (and how to) contribute to a professional or formal context. It also provides an item for the CV that might defy expectations of other people. Overall, the group aims to support aspirations and boost self-esteem - this year, personalised technology support has been a substantial enabler for them in reaching these aims.

Having Fun Together

The Young People's Participation group introduced weekly chats to respond to the social isolation people were experiencing when schools first closed. This started with twice a week, one morning slot and one afternoon slot. It was important for attendees that they had something other than an education session with which to engage. Schedules adapted when people went back in to school. Facilitators asked the group what they wanted – what day, what time – demonstrating their commitment to choice, and creating space for social support during uncertain times.

The group had lost face-to-face contact and had new members, but feedback suggests this group was able to maintain its relaxed atmosphere. This was attributed to the freedom within the group, keeping the humour and the freeform communication that is sometimes lost in other digital activities that are more rigid in format. Group rules encourage self-expression within a safe space – for example, it is allowed to swear, but not to swear at someone. Young people are encouraged to talk about anything they like (common topics are Disney, music and videogames) and to say it how it really is.

For daytime meetings, the Teams platform is used. Zoom is preferred for evening activities, particularly Zoom discos hosted by a local DJ. The discos feature a DJ in his living room with a full set-up of decks, sometimes him and his kids dancing, sometimes spotlighting other people dancing. These are 'live' synchronous activities, with lots of preparation time in advance to advise on engaging with device and the interface. Using a different platform for a different time of day helped to create some separation between the activities. The Zoom discos have created bonus fun, supporting the wellbeing of both staff and the young people. There has been a huge range of abilities participating, with young people dancing from their bed or round their living room – remote, but still having fun together.

Conclusions

Understanding digital disadvantage for disabled children, young people, and families requires an awareness of the physical context, psychological context, technological context and interpersonal context in which digital interactions take place. Digital disadvantage means that the benefits of digital are less likely to be achieved. This could deepen the inequality already experienced by disabled people - digital disadvantage can lead to reduced access to information, essential services and opportunities for personal development. Digital disadvantage has negative consequences for wellbeing and social participation and increases the risk of social isolation or dependence. Digital disadvantage is an issue that sits at the intersection of personal, interpersonal and societal processes (this is depicted in Figure 1).

Achieving beneficial outcomes from digital services requires digital advantage in the form of personal ability, capacity, confidence and a supportive social context. For example, many digital activities place high demands on dexterity, cognitive load and tolerance for frustration. The necessity of supportive persons in enabling and allowing digital activities draws attention to family dynamics, the home environment and pre-existing perceptions of technology use. During the pandemic, there was limited time to access and gain familiarity with new platforms, in the context of high care demands and an overload of virtual offerings. Long-term enduring issues relating to the inaccessible design of materials and device interfaces, and inadequate availability of high-speed broadband, have contributed to a deepening digital disadvantage during the pandemic.

Understanding the context of digital disadvantage:

Wider Context
- Cost and availability of devices and equipment
- Access to reliable internet connection
- Inaccessible schooling and public health information
- Cultural attitudes towards technology
- Design assumptions of language literacy
- 'Digital-only' services
- Fear and uncertainty of pandemic,

Social Context
- Limited informal social network or professional input
- Emotional wellbeing of family – (stress, worry, anxiety)
- Financial concerns and responses to pandemic context
- Amount of space and privacy at home
- Family attitudes towards technology use
- Availability of devices
- Level of functional IT skills

Personal Context
- Physical, sensory, cognitive and/or social impairments
- Loss of usual routine and professional support
- Emotional wellbeing – (stress, fear, uncertainty)
- Physical health fluctuations & personal care needs
- Typing ability and comfort on camera
- Previous online experiences
- Familiarity with digital etiquette
- Vulnerability to harm (perceived & actual)

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Analysis of UK OfCom data describes extensive and limited users in the population. Extensive and general users tend to have a favourable social context: they are of working age or older, with employment and/or a high standard of education. Limited or restricted users are more like to live rurally or to not own their own home, to have left education before university, or to have a health condition that impacts on daily life. Limited or restricted users are almost half of the population – there is clearly no one size fits all approach to improve digital engagement (Yates et al, 2020). There is growing evidence of limited or restricted digital use among younger people - however, disability is not adequately captured or explored in Ofcom's data.

Digital disadvantage is demonstrably connected to inequality in society – including inequalities related to geographical region, financial distress, overcrowded housing, language literacy and cultural variation. The cost and availability of reliable internet, devices and specialist equipment can be a substantial barrier to digital inclusion. People living with poor wellbeing and high stress are more likely to experience frustration and demotivation during technology use, especially if attempting new activities without social support. The availability of supportive and technologically confident relationships is variable between different social networks. Specialist knowledge of accessibility features and extra equipment can also be required by families or support persons, particularly for disabled children and young people.
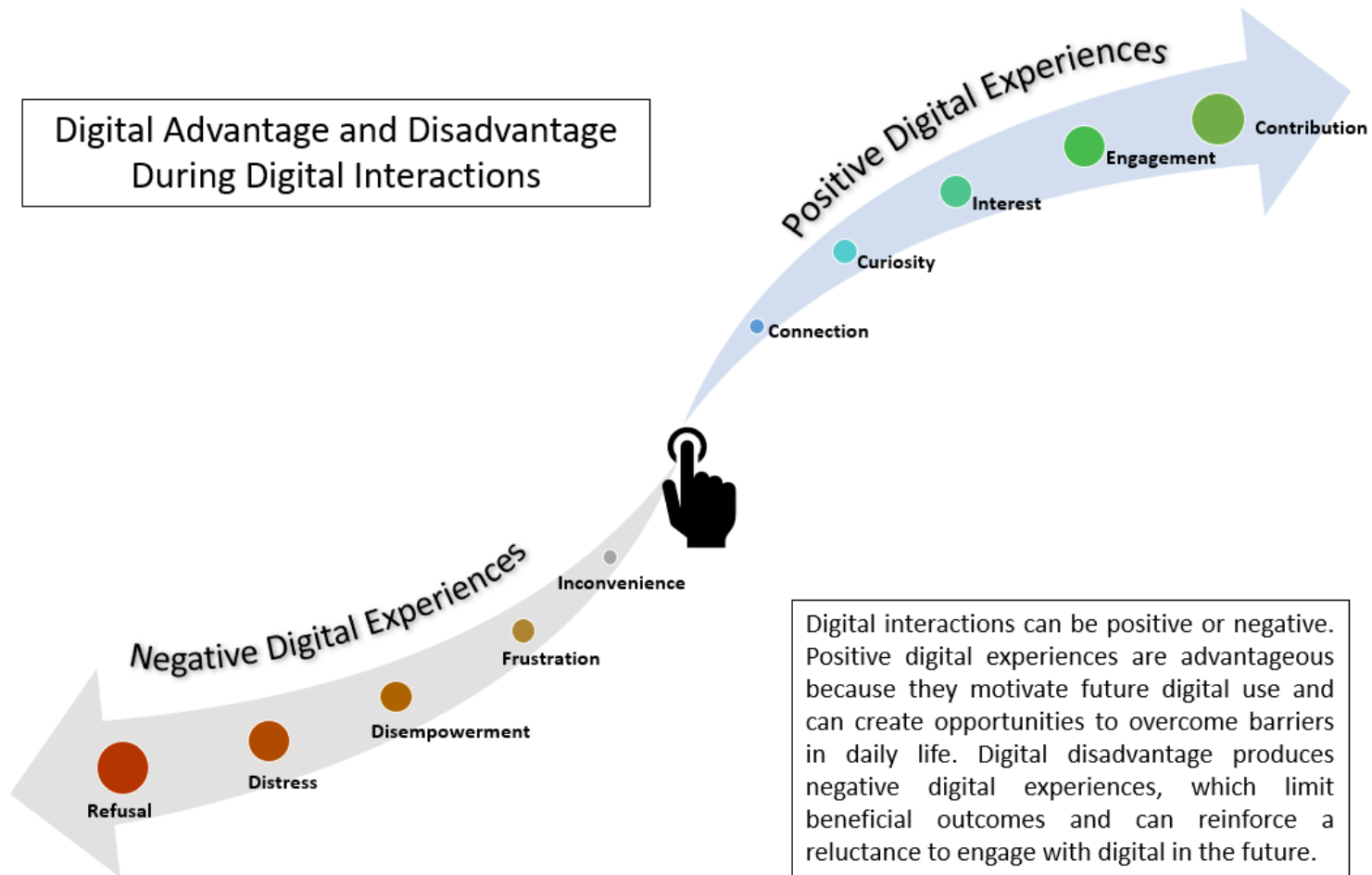
Although poverty is a factor in digital disadvantage, it is not the only one. Barriers can include digital confidence and cultural attitudes towards gender roles. Weaknesses in English language skills amplify the issues of poor connectivity during video calls and inaccessible information provision - it becomes exponentially harder to comprehend the content. Even with high levels of language proficiency, many people hold divergent attitudes towards technology that are not easily addressed by unfamiliar professionals. Despite having the appropriate devices, software and connectivity, they may not be comfortable on camera themselves or not want to show their home or children on camera.

The level of digital advantage enjoyed by one person is not fixed from day to day or static between different activities and platforms. We all demonstrate varied amounts of engagement and frustration – there might be some operations we perform daily, competently, and others that feel unfamiliar and intimidating. What was once referred to as a 'digital divide' between included and excluded people could be better described as a spectrum ranging from complete rejection of digital, to active participation and agency (Figure 2.) Even mild digital disadvantage, for example patchy internet connection, can diminish active participation, by placing someone in the passive observer role during a group video call.

Technology acceptance is a process, encouraged by perceptions that using the technology will be free from effort and risk. These perceptions are informed by the social network, community expectations and the individual's previous experiences. Positive experiences of digital during childhood and adolescence will be taken into

adulthood – digital advantage can open up opportunities in unexpected ways, whereas digital disadvantage is associated with negative experiences and impaired outcomes. Different digital services might encourage extensive contributions from those involved or foster the passive consumption of content. Teaching other people how to use technology or leading group activities could be characteristic of active participation in a digital world.

Digital Advantage and Disadvantage During Digital Interactions

Positive Digital Experiences

- Connection
- Curiosity
- Interest
- Engagement
- Contribution

Negative Digital Experiences

- Inconvenience
- Frustration
- Disempowerment
- Distress
- Refusal

Digital interactions can be positive or negative. Positive digital experiences are advantageous because they motivate future digital use and can create opportunities to overcome barriers in daily life. Digital disadvantage produces negative digital experiences, which limit beneficial outcomes and can reinforce a reluctance to engage with digital in the future.

Although important, digital might not be the priority for all families - particularly during the pandemic, when disruption to therapies and services has caused some children to lose developmental progress and experience increased pain or psychological distress. Digital disadvantage can become a reinforcing issue when digital barriers prevent individuals from reaching their goals (including access to essential services or information) so that their stress continues to increase, and technology-related frustrations become less tolerable. Challenges to mental health and increasing financial stressors are barriers to digital inclusion, within and beyond the pandemic.

Digital disadvantage has become increasingly relevant because responses to the pandemic have enhanced and expanded digital delivery of many aspects of daily life, including social support, healthcare, supportive services and education. Digitisation during the pandemic had led to improvements in accessibility for some people, with advantages seen that might leave some of us wondering why these changes weren't made earlier. However, this digital advantage risks being exclusively enjoyed by people who have access to or opportunities to use high standards of technology, connectivity, and relevant skills. Changes to digital practices within and beyond the pandemic are at risk of excluding people who have had limited opportunities or resources to try new things in the past year and people who need additional support to access technology.

There are logistical advantages of digital delivery that can be an advantage for service-users and service-providers. However, if digital disadvantage is unaddressed, it will lead to a worsening of outcomes for disadvantaged groups, because the individuals most in need of services become increasingly excluded from them. The centrality of digital to education and to work risks perpetuating inequality, as evidenced in the unequal opportunities and outcomes of digitisation so far (Yates & Lockley, 2020). Digital services who are not aware of the changing needs of their service-users are at risk of creating barriers to access that perpetuate digital disadvantage.

This report documents how the risks and consequences of digital disadvantage have deepened. Interventions towards digital inclusion can provide devices and technology support, but there is a concern on reach and effectiveness. Organisations that draw only from online networks or rely on professional referrals will be less able to reach digitally excluded individuals. Familiarity and confidence with digital interactions can enable individuals to navigate their daily lives, online and offline.

Understanding experiences from the pandemic can be informative for efforts to improve opportunities and reduce obstacles moving forward. Blended and co-designed service models might be able to capture the improved accessibility of events for some people, whilst being flexible enough to accommodate the varied needs of this population. Organisations seeking to balance choice and accessibility could look to develop hybrid models of service delivery.

This report concludes by offering guidance for the following:

- Digital Inclusion Interventions
- Practitioners and Service-Providers
- Schools and Educators
- Staff and Workforce Management
- Research
- Policy

Digital opportunities can enable disabled children and young people to be heard, to have fun, to learn, to connect with each other, and to participate more in society. Access to digital services and activities therefore creates opportunities to improve wellbeing and achieve personal growth. However, there are barriers to digital participation, including inaccessible design. Supporting a child or young person to use digital creates extra demands on parents and caregivers, and there isn't sufficient guidance available on how adults can best balance protection and agency for children online.

Disabled people have the right to be included in digital spaces, they have capacity to learn to use technology and should be supported to use technology. It is essential that government, providers and charitable leaders continue to collaborate on overlapping challenges moving forward from the pandemic. Above all, the diverse digital experiences and perspectives of disabled children, young people and their families should inform the next stages of technology design and digital transformation.

Guidelines and Recommendations

Digital Inclusion Interventions and Programmes

Digital inclusion interventions are best designed to be a package of support, that goes beyond devices: ideally including connectivity, structured support to achieve personal goals and a whole family approach. Users need to have frequent practice over an extended time period to develop digital skills.

Technology support should be personalised and long-term, providing specialist equipment where it is required and desired. Gaining familiarity with a new digital interface is a process which can be highly stressful in some contexts. People need support and actual input – the perception that help is available improves confidence to respond if something unexpected happens.

For disabled children and young people, support should include an ongoing assessment of needs – these will change over time. Assessment should prioritise the user's choice in what device to use and seek their input to identify personal priorities and goals. Interventions should aim to encourage active participation in the digital world, by creating rewarding opportunities for engagement and contribution.

It may be helpful to include device training for parents, caregivers, or support workers so that they are familiar with accessibility features and straightforward routes to achieve actions (not just passive activities like joining calls). Support workers and parents could benefit from more guidance in how to balance digital safety with autonomy and agency when caring for young people.

Digital inclusion initiatives are more likely to be rewarding and thus effective if they facilitate a social experience or relate to personal interests. For example, digital can create access to reciprocal social support, a platform for self-expression and information on any topic. Identifying relevant and appealing components for an intervention requires user collaboration. Co-design of intervention activities can lead to feelings of influence, agency and inclusion, whilst also improving the likelihood that the intervention will be effective.

There is a concern on reach, including to those who are offline or choosing to refuse digital services. Interventions need a coordinated way to extend their offering, because marketing and communication strategies that are solely online will be insufficient. Community-level organisations (including faith and community leaders, small local organisations and campaign or self-advocacy groups) might be able to improve reach through their offline networks.

Interventions need to be tailored to the needs and interests of particular groups: 'the digitally disadvantaged' is non-specific. People in different social contexts, with different disabilities and sensory impairments will have different experiences of digital.

Cultural identity, employment history and education experiences all influence attitudes towards technology. Intersectionality is relevant to the context of digital disadvantage and the experience of interventions.

A priority group for consideration are young adults in supported living settings, that may have previously attended an activity in person that they can't access through digital means. This group deserves targeted action towards social inclusion to prevent long-term exclusion.

Practitioners and Service-Providers

A comfortable digital space is: welcoming and friendly, with clear instructions, but not overly prescriptive in format. Provide simple accessible 'how-to' guides, in advance, and in hard-copy format where required – this can feel supportive and prevent frustration if technical difficulties do arise. Schedule sessions to allow for questions and technology-related delays at the beginning.

Communication before events can provide reassurance and improve the confidence of attendees. The quality of interpersonal connection matters to everyone involved. Of further benefit is to provide an "About Me" information page, with photographs and friendly introduction statements for children, young people and families, especially in advance of first-time meetings with professionals. This can be approached as an #hellomynameis for the digital age.

Make key information available in a 'low tech' format that considers demands on data for downloads. Opt for simple webpages with digestible chunks of information – these are more accessible than large downloadable files. Design for a small screen and keep functions simple - be aware of the prevalence of smart phone use.

Do not assume a high specification of available equipment or access to a home printer. Aim to communicate information as simply as possible. Minimise expectations of language literacy, and design for a variety of learning styles when creating content. Hard copies of additional documents and professional introductions should be provided in advance of formal meetings.

People might have low confidence, poor connectivity, or just a busy household. So be encouraging, but respectful if people choose not to turn on their webcam – their decision might be related to variable internet connection, privacy of other household members, or personal comfort on camera.

Create opportunities for peers to engage with each other, for example through shared activities that build interpersonal connection and useful peer support. Peer support can be encouraged through skilled group facilitation, and/or thoughtful matching of personal qualities and interests. However, there is a risk of harm if 'peer' status is assumed based on, for example, age or diagnosis only.

Include physical components in a digital service to vary the sensory input of an activity, and support feelings of companionship between people involved. Service design that includes both digital and physical components, and varied opportunities to participate, could be helpful to alleviate digital overload and screen fatigue.

'Digital-only' services might lead to safeguarding concerns by creating barriers between practitioners and children, restricting assessment and diagnosis, or the provision of effective emotional support. Note that distress arising from digital interactions may be undetected by service-providers and difficult to resolve. Ongoing review and integrated feedback are helpful in developing service models.

Hybrid models of service delivery may be useful - moving towards a blended model might mean keeping the advantages of digital services for some and maintaining the benefits of in-person contact for others. Overall, practitioners can promote informality and flexibility to encourage low-pressure engagement from families and young people.

Schools and Educators

Adaptation to online schooling occurred at pace and without coordination, even within the same school. Teachers responding to last minute closures and reacting towards the best fit for everyone meant that some did lose out. There wasn't a strategy in place to provide for those with 1-to-1 support or personalised education plans, and unnecessary complexity was created by teachers establishing their own working practices and operating without usual accessibility supports.

Lessons can be learnt from this disruption. Educational providers should establish increased attention on the needs of SEN pupils, including recognition of accommodations and additional equipment provided within school in planning for any future school closures.

Some pupils may have been able to complete their schoolwork if it had been provided by post in hard copy format. Developing blended lesson plans, with some work on paper, might enable more personalised remote learning in the future. It may improve engagement to include components that allow pupils to interact or work together on group projects. Physical activity and social interaction during home learning should be encouraged where possible.

Current rules mean that accessibility equipment is restricted to school use – it is granted for that environment, not for the pupil themselves. Providing accessibility supports for pupils to use at home all year round, not just during term time, would increase the pupils' digital capability and the parents' familiarity with necessary specialist equipment.

Feedback on laptop loan schemes suggests there were delays in providing equipment and that the equipment provided was occasionally unsuitable for the work being set by teachers or the needs of the pupils. These challenges might be alleviated by

ensuring a single point of access for schoolwork or that curriculum activity is preloaded onto the devices. Computer technicians and teaching staff should follow-up on the provision of devices, to identify and resolve digital barriers to education.

The academic performance of disadvantaged pupils is likely to have been hindered by differences in the home environment during lockdown, including the technology context and their access to quiet space for schoolwork. Moving forward, schools and educators should consider how they can proactively support all pupils to succeed.

Educators can explore the use of social stories as strategy to teach children about online activities and improve their understanding of digital etiquette, including basic privacy and security behaviours online.

Staff and Workforce Management

Transitions to digital platforms can be stressful for members of the workforce. Organisations can support their staff in the transition to digital by providing relevant training and reviewing the suitability of home equipment, including devices and internet package. Sustainable home working practices require a needs assessment for musculoskeletal health, for example considering where additional monitors, headsets, desk, chairs and keyboards may have benefit.

Staff resilience can be fostered through structured social support - professionals should feel connected to colleagues who are having or have had similar technology experiences. It is necessary to replace the social interaction of office spaces with regular opportunities for teams to communicate, express concerns and gain encouragement from each other. Increasing opportunities for staff to review what they are doing together may encourage open dialogue that allows for technology and other challenges to be identified and resolved.

Staff need clear leadership on wellbeing behaviours at work – recognising that boundaries between home and work have been dissolved, and the 'down time' of travel is lost. This includes: scheduling breaks between video calls, maintaining physical activity and including time for relaxation activities, particularly during times of stress.

Expectations and practices around technology should be clearly communicated, and this communication should be two-way, giving trainers and leaders the opportunities to address challenges and barriers around new digital practices. Actively seeking and integrating feedback from service-receivers can be motivational for staff working remotely, who may feel less involved in successes than they would during face-to-face working.

It is unhelpful to have silos between staff with IT skills and staff that understand disability. Moving forward, supportive professionals may require a minimum standard of digital capability, so that they can facilitate disabled children, young people and

families in their own use of technology - recruitment could test digital skills and establish appetite to learn. IT staff should have some understanding of accessibility challenges and available solutions – recruitment could consider interpersonal communication and problem-solving skills.

Professionals should avoid working in isolation, even when working remotely. For example, if hosting a group zoom, there should be separate people facilitating the group and making notes, with scheduled time for these people to debrief afterwards, particularly on any safeguarding concerns.

Organisations could have 'digital champions', with remit to consider service provision from a digital disadvantage perspective, who deliver digital training and accessibility sessions, and work towards digital inclusion internally and externally.

Research and Data Collection

There is a need for applied research that moves beyond the digital inclusion/exclusion binary. This report documents numerous barriers that can lead to digital disadvantage: active participation in the digital world requires more than simple access to an internet-enabled device. However data collection methods amenable to capturing this nuance are in their infancy.

Structured conversations could be used in practice to gain insight on an individual's or a family's digital ability and capability, understanding their experiences of digital challenges and identifying areas of disadvantage amenable to intervention – research can help to develop guidance on these conversations.

Research and data collection must not assume that all disabled people fall into one homogenous group. People with visual impairments, with communication or cognitive impairments, with multimorbidity and those who have difficulties leaving home, will all have different experiences of digital disadvantage.

Mixed methods research is needed to identify priority groups and to explore multi-cultural experiences of digital. Aims would be to understand more about the influence of culture and social identity on attitudes to digital and thus improve the reach and effectiveness of digital inclusion interventions.

More research into universal design and inclusive adaptation is needed so that design requirements can be better understood. Academics and statutory providers might work with industry partners to advocate for user-centered design and improved accessibility.

Since digital engagement usually requires active input (or at least permission) from support relationships, the caregiver can be acting as a helpful assistant or a restrictive gatekeeper, or both, in different households and for different activities. The development of these roles and their contributions to ongoing relationship dynamics is an area worthy of further investigation.

An unanswered question relates to how intense caregiving responsibilities might digitally disadvantage parents - they might be less familiar with some digital platforms if they are required to leave the workforce or education early to provide care for their child or children. More research is needed into the digital needs of families with disabled children.

Routine data collection on disability for children, young people and families should be improved, for example to give information on digital activities cross-tabulated by age and disability status. Within this project it was not possible to estimate the proportion of disabled young people who are digitally disadvantaged.

Digital access does not equal proficiency, so to improve outcomes there is a need to better understand functional IT skills across the population, through better data on different disability groups, regions and ages.

There is a need for more research into advantages, challenges, and recommendations of hybrid/blended service models, that include digital and in-person delivery. This is especially the case for education and healthcare, where unanticipated consequences of digitisation are poorly understood.

Policy Makers

Policy makers can respond to digital disadvantage with measures to improve the availability, affordability, and design of the digital realm. This might draw from the New Zealand strategy, which includes measures towards affordable connectivity, available devices at low or no cost, wrap-around support for the newly connected and digital skills training provision (New Zealand Department of Internal Affairs, 2019). The multi-dimensional nature of digital disadvantage means that focusing on just one of these components in isolation will have limited impact.

Disability and poverty are substantial issues driving digital disadvantage, but they are not the only contributors. Priority groups include minority cultures, people without professional digital experience, and rural communities who have adapted to inadequate connectivity. Improving internet infrastructure and access across the whole country should be a priority.

Developments towards universal design are important to overcome barriers experienced by people with limited dexterity or some sensory impairments. Governments should encourage user-centered design approaches and inclusive adaptations, particularly within statutory services.

It is not acceptable for essential public health information to be provided in inaccessible formats. There is a need for clearly communicated guidelines and enforced regulations, to improve accessibility of information and essential services, including healthcare and education.

The benefits of the digital realm are most pronounced when an individual is able to actively participate, which means that digital inclusion initiatives are most valuable when outcomes prioritise active participation over the passive consumption of online media. Policy changes that improve user confidence and encourage digital contributions are likely to produce meaningful long-term change for digitally disadvantaged individuals.

Plans can be put in place now that minimise the unequal impact of school closures during disruptive events of the future. Accessibility equipment, if needed within school or work, is probably needed within the home environment too.

Disabled children, young people and their families were disproportionately affected by Covid-19 and many experienced digital disadvantage. Targeted digital inclusion programmes must be included in the Government's Covid-19 recovery plans. Policy makers should also ensure that digital access for disabled children and families is fully covered in all relevant disability policies, including the National Disability Strategy and the forthcoming SEND review.

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Appendix 1:

Freedom of Information Request

A freedom of information request was sent on 23/03/2021 with a response provided 22/04/2021. The following information was requested:

1. The proportion of young people aged 16 to 24 years who are defined by the Equality Act as disabled and not in education, employment, or training in 2020.
2. Information on the number or proportion of children and young people who are disabled or with life-limiting illness living in lone parent households, with most recent available data.
3. The number or proportion of children and/or young people who are disabled or with life-limiting illness who live in a household without internet access, with most recent available data.
4. Information on the number or proportion of children and young people who are disabled or with life-limiting illness, in households where adults are not in education, employment or training.
5. Information on the number or proportion of children and young people who are disabled or with life-limiting illness, living in poverty.

Not all of this information was available due to limitations in data collection and cross-tabulation between data sets. The available information is presented in Part 1 of this report and subsequent appendices.

Appendix 2:

Outcomes for Disabled Adults in UK

- For the year ending June 2020, 23.0% of disabled people aged 21 to 64 years had a degree or equivalent as their highest qualification, compared with 39.7% of non-disabled people. In addition, 15.1% of disabled people had no qualifications, which is almost three times the proportion of non-disabled people (5.4%).

- Across English regions, London had the highest proportion of people obtaining degrees for both disabled people (34.6%) and non-disabled people (57.5%), however this region also had the largest significant disparity between disabled and non-disabled people (22.9 percentage points). The North East had a large disparity for obtaining no qualifications (12.5 percentage points), 18.5% of disabled people compared with 6.0% for non-disabled people.

- Around half of disabled people aged 16 to 64 years (52.1%) in the UK were in employment compared with around 8 in 10 (81.3%) for non-disabled people (July to September 2020). Disabled people with the lowest employment rate were those who reported their main impairment to be autism (21.7% employed) or learning difficulties (26.5% employed). The employment rates for disabled people were similar between men and women (52.2% for men and 52.0% for women). The North East had the lowest employment rate for both disabled and non-disabled people (46.4% for disabled people, 79.4% for non-disabled people) and also had the largest disparity in employment rates between disabled people and non-disabled people (33%).

- 66.6% of 16-19 year olds with a disability are considered economically inactive, compared with 54.5% of their non-disabled peers. 42.9% of disabled 20-24 year olds are economically inactive compared with 22.8% of their non-disabled age group peers. 32.5% of disabled 25-29 year olds are economically inactive compared to 8.9% of their non-disabled age group peers.

- A higher proportion of disabled people aged 16 years and over in England were involved in civic participation (41.5%), such as signing a petition or attending a public rally, than non-disabled people (35.1%) (year ending March 2019). Disabled people were just as likely to have been involved in civic

consultations, civic activism and social action as non-disabled people. Similar patterns were seen when comparing disabled and non-disabled people of each sex. Young disabled people aged 16 to 24 years were more likely to be involved in civic participation (46.9%) than non-disabled (30.9%) people of the same age, a significant disparity of 16.0 percentage points.

- Disabled people showed similar proportions of participation in either formal or informal volunteering (37.5 % for formal and 55.7% for informal) in the past 12 months as non-disabled people (39.8 % for formal and 52.1% for informal). Similar trends were seen when comparing disabled and non-disabled people by sex. Nearly 6 in 10 (59.5%) disabled people aged 16 to 24 years participated in informal volunteering compared with 43.8% of non-disabled people in that age group, a significant difference.

- Disabled people aged 16 to 64 years in the UK were less likely to own their own home (40.9%) than non-disabled people (53.4%), and more likely to have rented social housing (at 24.9% compared with 7.8%) (year ending June 2020). The housing situation of disabled people varied across age groups. Young disabled people aged 16 to 24 years were as likely to live with parents as non-disabled people of the same age, with similar proportions seen for each (71.7 % for disabled people, 74.4% for non-disabled people). [Note that these statistics consider living with parents to also include students at boarding school or those in halls of residence, as it is considered that their parents' home is their main residence and the student accommodation is temporary.]

- Disabled people's (aged 16 to 64 years) average well-being ratings in the UK were significantly poorer than those for non-disabled people for happiness, wellbeing and life satisfaction measures. The greatest disparity was in average anxiety levels - higher for disabled people at 4.47 out of 10, compared with 2.91 out of 10 for non-disabled people (year ending June 2020). Women reported significantly higher anxiety levels than men, this was consistent for both disabled and non-disabled people. Compared with the year ending June 2019, disabled people had a significantly higher average anxiety rating in the year ending June 2020.

- Loneliness data are taken from the Community Life Survey (CLS), covering England for the year ending March 2019. A significantly higher percentage of disabled people aged 16 years and over felt lonely compared with non-disabled people. The proportion of disabled people (13.9%) who reported feeling lonely "often or always" was nearly four times that of non-disabled people (3.8%). Similar proportions were observed for both groups in the year ending March 2018. The proportion of disabled people feeling "often or always" lonely varied by age – 19.6% of 16 to 24 year olds, 20.7% of 25 to 34

year olds, 20.6% of 35 to 49 year olds, 13.9% of 50 to 64 year olds, and just 7.2% of disabled people over the age of 65. The proportion of people who felt lonely was highest in disabled people who were limited a lot (23.6%), compared to limited a little (9.2%), and non-disabled people (3.8%).

- Around 1 in 7 (14.3%) disabled people aged 16 to 59 years in England and Wales experienced domestic abuse in the last 12 months, compared with about 1 in 20 (5.1%) non-disabled people; disabled women (17.5%) were more than twice as likely to experience domestic abuse in the last year than non-disabled women (6.7%) (year ending March 2020). Disabled people aged 16 to 24 years were almost three times more likely to have experienced any form of domestic abuse in the last year (19.5%) than non-disabled people of the same age (7.3%).

Appendix 3:

Social Impacts of Coronavirus

- Over 8 in 10 (83%) disabled people compared with around 7 in 10 (71%) non-disabled people said they were "very worried" or "somewhat worried" about the effect that the coronavirus (Covid-19) pandemic was having on their life in September 2020; for disabled people, but not for non-disabled people, this is a similar level to that reported earlier in the pandemic (86% and 84% respectively in April 2020).

- Around 5 in 10 (50%) disabled people who were receiving medical care before the coronavirus pandemic began, indicated that they were either currently receiving treatment for only some of their conditions (29%), or that their treatment had been cancelled or not started (22%).

- Over 4 in 10 (45%) of those disabled people who had reported receiving a reduced level of treatment or had their treatment cancelled in September 2020 reported that they felt their health had worsened in this time; in July 2020 this proportion was one-quarter (25%).

- All well-being ratings of disabled people remained poorer in September 2020 compared with a similar period prior to the coronavirus pandemic; almost half (47%) of disabled people reported high anxiety (a score of 6 out of 10 or higher) in September 2020 compared with less than a third (29%) of non-disabled people.

- Disabled people reported more frequently than non-disabled people in September 2020 that the coronavirus pandemic is affecting their well-being because it makes their mental health worse (41% for disabled people and 20% for non-disabled people), they are feeling lonely (45% and 32%), they spend too much time alone (40% and 29%), they feel like a burden on others (24% and 8%), or have no-one to talk to about their worries (24% and 12%).

- Disabled people more often than non-disabled people indicated that the coronavirus affected their life in terms of:
  - well-being (62% for disabled people, compared with 42% for non-disabled people)
  - health (28% compared with 7%)

- o access to healthcare for non-coronavirus related issues (43% compared with 20%)
- o access to groceries, medication and essentials (31% compared with 12%)
- o relationships (30% compared with 21%)

- Of all the worries they had, more than 1 in 4 (27%) disabled people were most concerned about the impact on their well-being and more than 1 in 10 (13%) were most concerned about the access to healthcare and treatment for non-coronavirus related issues, and a lack of freedom and independence (10%).

- Access to healthcare and treatment for non-coronavirus related issues was less often identified as a main worry for non-disabled people (5%) compared with disabled people (13%), as was effect on health (1% for non-disabled people and 7% for disabled people).

Appendix 4:

ONS Data on Internet Access & Usage

- According to ONS, 2020 data: 96% of all households have internet access and 100% of households with children have internet access. 89% of adults use the internet daily or almost daily, 5% did not use the internet in the last 3 months. Age differences reflect that 100% of 16-34 year olds use the internet daily, 67% of those over the age of 65 year old use the internet daily. Across all ages, 84% of disabled people use the internet daily compared to 91% of non-disabled people (total sample 89%). [Queries have been made regarding sampling strategy in terms of population reach and representativeness of people without internet access].

- Frequency of different internet activities showed substantial differences. At the time of data collection in 2020, 85% sent or received emails in the last 3 months, 76% used internet banking, 49% made video or voice calls over the internet in the last 3 months, 21% made a medical appointment online, and 8% accessed their personal health records online in the last 3 months. These activities showed differences by age and disability status, however analysis has not been cross tabulated by these categories.

- 16-24 year olds were more or as likely as the total population to engage in all activities included. Compared with non-disabled people, disabled people across age groups were less likely to use emails (78% vs 87%), use internet banking (65% to 79%), make video calls (37% vs 52%), or look for health related information online (55% vs 61%). However, they were more likely to make a medical appointment online (23% vs 20%), use online health services such as prescription requests (23% vs 13%) and access personal health records online (13% to 7%).

- Disabled people were less likely to access online learning material (16% vs 23%) or do an online course (11% vs 14%) than non-disabled people, across all age groups. They were less likely to do online shopping (81% vs 88%) or to use cloud computing (37% vs 53%). These activities showed big age differentials.

- Young people (16-24) were aware of privacy concerns and protection of personal data, at equivalent or higher rates to older age groups For example, 83% were aware that cookies could be used to trace internet activity, and

73% restricted access to location tracking. An exception was that young people were less concerned with tailored advertising than other age groups (45% compared to 56% of the full sample). However, people with disabilities across all age groups suggested a lower awareness than non-disabled people – 69% were aware of cookies compared to 76% non-disabled people, and 49% restricted access to location compared to 55% non-disabled people. Concern over tailored advertising was relatively equivalent in these two groups (55% vs 57%).

- 98% of 16-24 year olds report they have a smartphone for private use (84% of total population sample). The proportion of disabled people across age groups with a smartphone was lower than non-disabled people (76% vs 86%). Control of personal data on a smart phone was more common for young people (87%) than the total sample (68%); and less common for disabled people (64%) than for non-disabled people (70%). Disabled people were more likely to be concerned about security or privacy of the 'Internet of Things' than non-disabled people or young people and were less likely to use internet-connected entertainment, home energy controls, or wearable devices.