Designing for Digital Inclusion in Healthcare

Seminar 2: Barriers that exclude people from digital health services, and how to remove them

Intro

Katie Heard

Head of Research, Data and Insight at Good Things Foundation

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Digital inclusion and the VCSE H&W Alliance

VCSE Health and Wellbeing Alliance: Strategic Priorities 23 - 24

This infographic sets out the key areas for the HW Alliance's collective and collaborative work over the next year.

VCSE health & wellbeing alliance

Policy areas

Key areas of policy making the HW Alliance will work collaboratively on.

- Primary care
- Maternal health
- Mental health & suicide prevention
- Social prescribing
- Social care

Cross-cutting themes

Topics which overlap multiple policy areas which are important to the HW Alliance.

- Digital
- Co-production
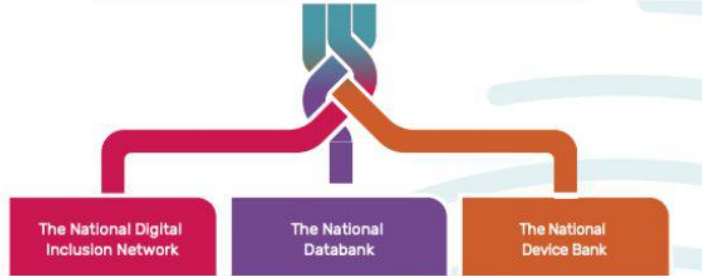- Data
- Cost of living

Horizon scanning

Responding to new areas of strategic importance, for example:

- Emerging strategic priorities at system partner organisations, such as the development of a new strategy, an important consultation, a new policy initiative.
- Issues or concerns raised by people, communities and voluntary sector organisations about their health and care.

- The Voluntary Community and Social Enterprise (VCSE) Health and Wellbeing Alliance (HW Alliance) is a partnership between sector representatives and the health and care system.
- It enables the sector to share its expertise at a national level with the aim of improving services for all communities.
- Our focus spans many of the Exclusion Health Subgroups
- Digital is a core cross cutting theme for all our work

Good Things Foundation

Good Things Foundation - Fixing the Digital Divide

Designing for Digital Inclusion in Healthcare Series

These seminars aim to draw together the knowledge colleagues from across the Health and Wellbeing Alliance have collectively built over the last few years

A three part series sharing insights and learning from the VCSE Health and Wellbeing Alliance on minimising health inequalities and digital exclusion in healthcare.

Seminar 1:

Exploring the intersection between digital and health inequalities

Tues 23rd Jan, 12:30 - 14:00

Seminar 2:

Barriers that exclude people from digital health services, and how to remove them

Wed 24th Jan, 12:30 - 14:00

Seminar 3:

Designing inclusive digital healthcare services - lessons and principles

Thurs 25th Jan, 12:30 - 14:00

Recordings of all three seminars will be made available following the events

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Yesterday we heard.....

Exploring the intersection between digital and health inequalities

Knowing which groups are at risk of being excluded from your services (digital and non-digital) matters

Digital service and system design can create or exacerbate the health inequalities - avoid 'digital by default'

Digital inclusion is promoted in health and care policy - use this to strengthen the case for investing in inclusive digital services (where appropriate)

Consider the cost to the end user of accessing (eg buying the tech) or not accessing your digital services

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Seminar 2: Exploring the barriers that exclude people from digital health services, and how to remove them

The barriers to digital inclusion are fairly consistent.

Using the guidance on mitigating risks of digital exclusion for those facing wider health inequalities, we will share with you information on how these barriers present themselves in healthcare settings, and how they can be mitigated in the design of new products and services.

We're delighted today to be joined by colleagues from:
- Hospice UK,
- Race Equality Foundation and
- Barnardos.

They will share their knowledge, advice or solutions on how to address these inequalities for the groups that they represent.

Overview of seminar

12:35 **Katie Heard (Good Things Foundation)**
Exploring the common Barriers to Digital Inclusion

12:55 **Jamie Hill (Hospice UK)**
Health inequalities and digital exclusion faced by people in Hospice Care

13:05 **Jabeer Butt (Race Equality Foundation)**
Health inequalities and digital exclusion faced by people in Ethnic Minority Groups

13:15 **Natalie Woods and Karen Marlton (Barnardos)**
Health inequalities and digital exclusion faced by Parents and Families

13:25 **Q & A**
Leave your comments and questions in the chat panel throughout the session.

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To help us understand who we're reaching and the value of the seminars

1. Which sector do you work in?

2. How much knowledge do you feel you currently have about digital inclusion and access to healthcare?

3. How capable do you currently feel to identify ways to improve digital inclusion in healthcare?
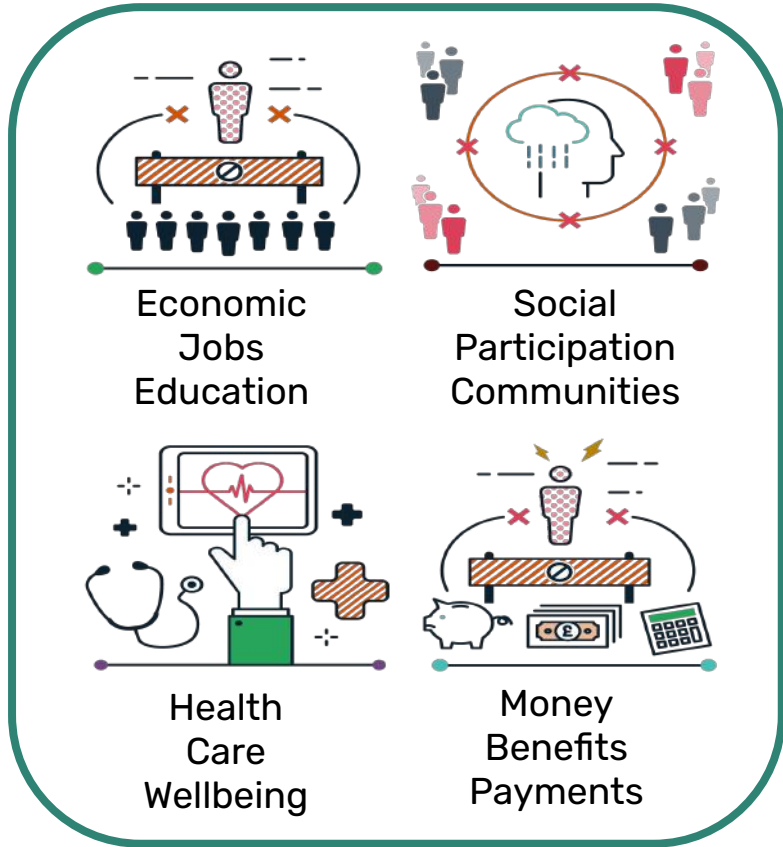
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Exploring the barriers that exclude people from digital health services, and how to remove them

Katie Heard

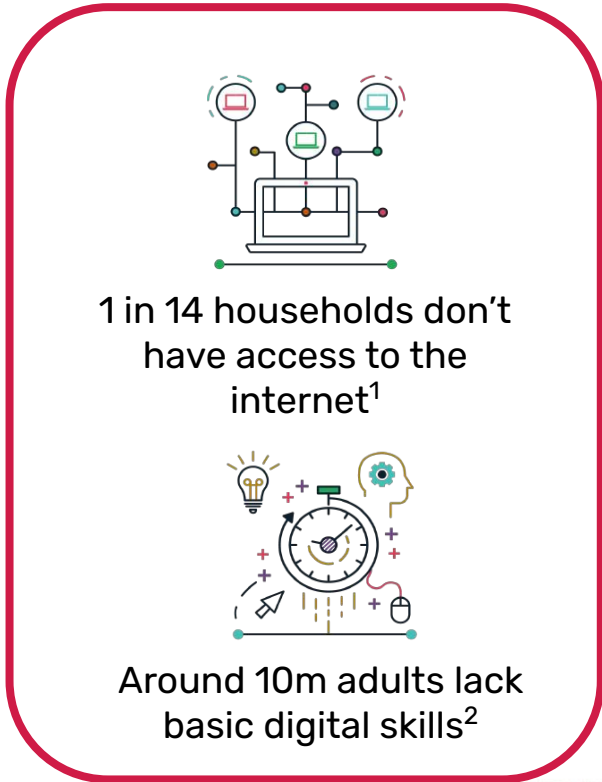Head of Research and Data Insights at Good Things Foundation

katie.heard@goodthingsfoundation.org

Services Moving Online Excludes many

Economic
Jobs
Education

Social
Participation
Communities

Health
Care
Wellbeing

Money
Benefits
Payments

Services moving online are not available to all due to lack of access or skills

1 in 14 households don't have access to the internet[1]

Around 10m adults lack basic digital skills[2]

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Limited digital use is linked to poverty as well as older age

▼ Compared to EXTENSIVE USERS ▼

NON-USERS are...

2 x *more* likely to have a **disability** or **health condition**

12 x *more* likely to be **over-65**

LIMITED USERS ARE...

5 x *more* likely from **low income** households

6 x *more* likely to be **over-65**

Intersectionality with some **protected characteristics** and other circumstances and factors
- **Inclusion health** groups
- **Where you live** – connectivity; deprivation; and available support

Source: Digital Nation 2023 (analysis of Ofcom data)

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For many the barriers to digital inclusion are consistent

Access

Skills & Confidence

Motivation

Trust and Feeling Safe

Space (Physical)

Support

Independence, choice and control

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Access and Space

Access:
Internet access – there are many aspects which all have to be in place (alongside having the skills and/or support to use the internet safely and confidently)

Space (Physical)
Access to a private and/or safe and confidential space to use the internet. For example, to do an online health consultation or for remote monitoring, or anything where confidentiality, privacy and security are required

- Good mobile or broadband coverage, speed and signal
- Suitable, appropriate device to access a digital service (via app / browser)
- Sufficient data to access the digital service
- Sufficient electricity to keep their device charged
- A printer or easy access to a printer (may be required or assumed)

Factors impacting negatively on this include:
- Not having a personal device with sufficient mobile data
- Reliance on using a shared device kept in a public or common area
- Living in overcrowded housing or housing with limited private space
- Living in an abusive home environment
- Temporary or transient accommodation (impacts data connectivity)

Skills, confidence and Motivation

Skills and Confidence
Basic digital skills for life (see Essential Digital Skills for Life, Gov.uk) For example: has an email or social media account; can find and download an app; use a search engine; understand 'padlock' sign; avoid online fraud

Motivation
Low motivation to use a digital service or tool

No, low and limited digital literacy can overlap with other areas of skills:
- Basic literacy and numeracy
- English (or Welsh) language proficiency
- Health literacy – e.g. understanding patient information, knowing where to find trustworthy information and help such as NHS 111
- Media literacy – e.g. understanding not everything on the internet is true

- Concerns about digital services replacing face-to-face or phone in general
- Concerns about losing the option to access / revert to face-to-face support
- Lack of confidence to use a digital service, and use it safely and independently (e.g. in case you don't have access to support when needed)
- Lack of belief that the digital service will deliver a better or faster outcome
- Lack of support – impacting on confidence and belief in the value of digital

Support, Independence, choice and control

Support
There is a positive relationship between internet use and confidence and people's personal social relationships.
In person, local, friendly can build skills and confidence

Independence, Choice and Control
Digital skills and access can enable independence, save time and money, and enable self care.
Not everyone will want to, or be able to, use digital health and care tools safely

Awareness is low about available support
- To build digital skills and confidence (e.g. Good Things Foundation, Learn My Way)
- To improve accessibility for disabled people (e.g. AbilityNet's helpline; free software to support accessibility)
- To train practitioners to be digital champions (e.g. Digital Unite's training).

- Keeping all channels open is essential to avoid discriminating against people who lack the access, skills, trust and support to use digital services
- Everyone can experience times of greater 'vulnerability' to online harms (for example, at times of stress or life transition)
- Using 'proxies' to access digital services and do online transactions (e.g. family, friends, carers acting on someone's behalf) has implications for data privacy and choice and control

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Trust and feeling safe

Trust and feeling safe
People worry about who can see their data, losing face to face services building on previous negative experiences

Low trust or mistrust of technology generally
- Concerns about surveillance technology, cybersecurity risks
- Concerns about how personal data will be used, shared and kept safe
- Concerns about technology going wrong
- Concerns about misinformation and disinformation, fraud and scams

Low trust in one's own abilities to use technology, especially where access to tech support is limited and/or would have to be paid for.

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Emphasise the positives
- Digital options can remove barriers for some that have been excluded previously
- Co-designing solutions means services are more likely to meet needs

Watch outs
- Keeping multiple routes (online and offline) to access services enables patient choice and equality of access to your services
- Barriers to digital services can compound existing non-digital barriers
- Technology and access is constantly changing - so be ready to adapt and change your approach for an individual or when a new service comes online
- Consider digital inclusion and design as part of your service - addressing wider barriers can make services more accessible
- Who is providing the support - already stretched staff, volunteers, VCSE organisations, family members - this impacts on sustainability

# Barriers to digital inclusion in palliative and end of life care

Jamie Hill, Digital and Web Product Manager

Hospice UK (on behalf of the palliative and end of life care consortium)

Health inequalities

Health inequalities and hospice care

- Data from England between 2017 and 2019 shows that Healthy life expectancy (HLE) at birth among males living in the most deprived areas was 52.3 years, compared with 70.7 years among those living in the least deprived areas.[1] This amounts to a difference of 18.4 years (almost two decades) in "Good" general health between these populations across their life course.

- On average, people living in more deprived areas have shorter lives and spend more time living with diagnosed long-term illness.
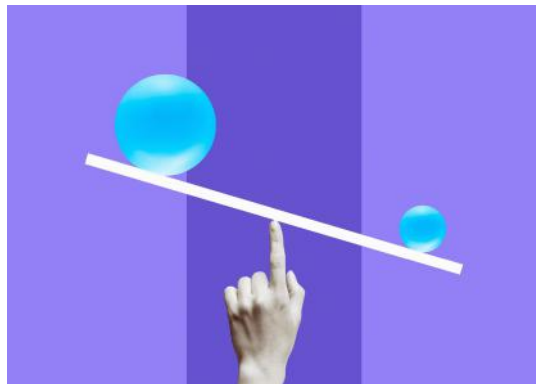
Inequity of access to hospice care

- Some communities continue to experience inequitable access to hospice care, including:

  - The oldest people

  - Racialised communities

  - People with non-cancer illnesses

  - People living in rural areas

  - People living in areas of high socio-economic deprivation[2]

How digital tools can be useful in hospice care

hospiceUK

Hospice care goes beyond hospice buildings

- Increasing pressure on palliative and end of life care services with a projected 25% increase in need for palliative care over the coming 25 years.[3]

- Fewer than 5% of people who die each year die in a physical hospice building.[4]

- Over 300,000 people are cared for by a hospice each year.[4] Most care is delivered in the place where people ordinarily reside e.g. private homes, care homes.

- Hospices do not care only for people in the last days of their lives, but for people living with all kinds of complex conditions and difficult symptoms. They also support unpaid carers, families and friends, both before and after a person's death. Increasingly this can mean supporting people who live far from the hospice building.

The pandemic showed that digital services can be used to deliver hospice care

- Catchment areas covered by hospices can be very large, with people having to travel long distances when they are very unwell. This is a particular challenge in remote and rural areas.

- Covid-19 restrictions led many hospices to start delivering services virtually, including outpatient services, such as breathlessness and art therapy groups, psychological support, and welfare advice.

- Digital tools can be used to track symptoms of people being cared for at home in real time, making it easier for community teams to prioritise caseloads and help people receiving care and those caring for them feel more in control.

Ways hospices are using digital services

Research for this work revealed that the use of digital services in palliative and end of life care is still in its relative infancy. However, some of the ways they are currently being used include:

- Remote consultations

- Virtual wards

- Remote symptom/outcomes monitoring

- Bereavement support services

- Outreach services for people living with long-term illnesses

- Facilitating multidisciplinary/multi-agency working

Recent data from Hospice UK's member hospices suggests that around 40% of hospices across the UK are currently offering some kind of virtual service.

Barriers to inclusion

Barriers to digital inclusion

Anyone can become digitally excluded, through a lack of connectivity, access, skills and/or motivation, but some groups, who are already negatively affected by health inequalities are more vulnerable.[5]

- **Connection** – Do people have adequate and reliable devices and internet connection that enable them to engage with digital services?

- **Accessibility** – Are the digital tools available accessible to the people for whom they are designed and do they meet their specific needs?

- **Skills** – Do people have the digital skills needed to use tools and services in a way that benefits them?

- **Motivation** – Do people believe that digital services can be useful to them and add value beyond the status quo?

Context-specific barriers to digital inclusion

- Many people receiving palliative and end of life care are older and many have disabilities. According to NHS Digital (now part of NHS England), older people and people with disabilities are among the groups more likely to be digitally excluded than others.[6]

- The reactive nature of solutions developed during the pandemic meant that the user-centred design principles essential to developing inclusive digital services were largely bypassed. Impressive innovation took place in the moment, but it has been difficult to sustain momentum.

- Most hospices are independent charities, with limited public funding (1/3rd on average[7]) so do not automatically have access to NHS IT systems. They may be using systems that are different to those used by patients' GPs etc. This can make it even more difficult for people to adapt to use new digital services.

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Recommendations

Top tips for providers

1) Take time to understand the needs of people at the end of life, carers, staff and volunteers when designing and using digital solutions

2) Encourage collaboration and shared learning between providers to prevent duplication and with specialist organisations to increase digital skills, confidence and trust among all user groups

3) Support and invest in people who are passionate about adopting and promoting digital health

4) Invest in the digital skills of staff

5) Provide online/digital services in appropriate community languages and accessible formats, ensuring that they meet the Accessible Information Standard.
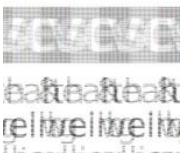
Developing digital services for hospice care

Engage with developers (if needed). Plan for cycles of evaluation and improvement from the outset.

Take time to train staff and support people to use the tools and devices required.

Test your solution over a time-limited period, measuring according to the definitions of success from Stage 2.

Assess and evaluate the outcomes of your initial pilot. Investigate whether sustainable funding is available and present your evaluation to potential funders.

Reach out to other hospices and to your local ICB network to understand their use of digital services, aiming to avoid duplicating work.

If the intervention is effective and financially viable, refine through consultation with staff, patients and carers and relaunch.

Bring together potential users of the tool, including patients, carers and staff. Work with them to understand their needs, define what success will look like and how to measure it.

Define the problem/ gap you are trying to solve. Ideally involve staff, people with lived experience and carers.

Share what you have learned with relevant organisations within your ICS.

START

END

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System-level recommendations

1) Allocate adequate digital health funding to providers and networks, including for crucial basic digital infrastructure within the hospice sector

2) Invest in digital skills training for staff across the health and care system

3) Support providers to maintain in-person options while developing digital services and connect them with relevant expertise from beyond the health and care system.

References

Stone E. *Digital exclusion & health inequalities: Briefing paper.* Good Things Foundation. 2021. https://www.goodthingsfoundation.org/insights/digital-exclusion-and-health-inequalities/ [Accessed 17 July 2023]

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Thank you!

hospice^{uk}

Designing for Digital Inclusion in Healthcare

Race Equality Foundation

Jabeer Butt and Jahan Foster Zabit

Who we are:

Led by Black, Asian and ethnically minoritised people, we are an evidence-based, policy and practice charity working to tackle racism and racial inequalities.

Our vision:

A society without racism.

Our mission:

To tackle racism in UK society and positively transform the lives of our Black, Asian and ethnically minoritised communities.

VCSE health & wellbeing alliance

A series of **Better Health** and **Better Housing** briefing papers
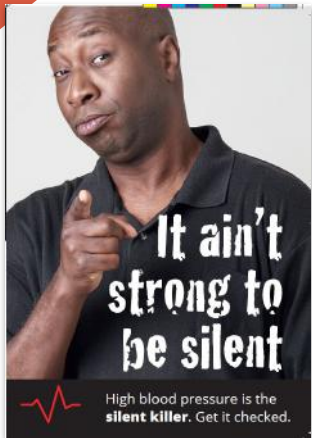
A community based approach to improving blood pressure monitoring
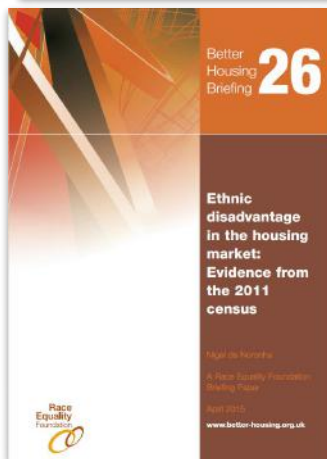
A literature and evidence review of racial disparities in mental health
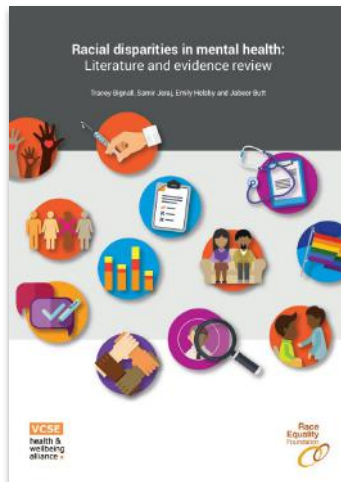
Report on physical health checks for people with severe mental illness
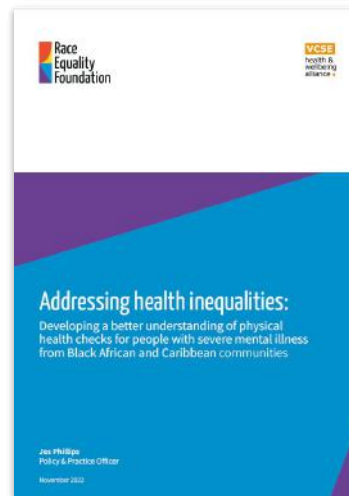
A series of briefings as part of the race equity collaboratives on the impact of Covid 19 and what should happen next

Examples of our work

www.raceequalityfoundation.org.uk

Introduction to Health Inequalities & Data on Digital Exclusion

- Evidence reveals ethnic minority groups face barriers in healthcare access, resulting in poorer health outcomes

- Issues include systemic problems in service operations and a lack of ethnic minority representation amongst the workforce

- Research indicates ethnic minorities and older individuals are less likely to use health apps and express concerns about data usage

- Barriers impacting digital inclusion include: mistrust of data use by Government organisations, lack of digital literacy, language barriers, limited access to digital tools, economically inactive and digital skills

Mistrust of Intended Use of Data by Government Organisations

- Lack of trust in healthcare professionals due to systemic problems

- Mistrust exacerbated by lack of representation

- Reluctance to use care management apps among ethnic minorities

Lack of Digital Literacy

- Older generations face greater barriers due to lower digital literacy
- Heavy reliance on others for digital navigation
- Limits independent engagement with healthcare decisions

Language Barriers

- Lack of available interpreters results in reliance on family and friends

- Technology must ensure accurate language translation

- Bridging cultural differences is essential for effective communication

Limited Access to Digital Tools

- Shift towards digital widens health inequalities

- Minority ethnic groups often delay seeking care due to digital technologies

- Cultural insensitivity in digital consultations may cause discomfort

Policy Recommendations

- Demonstrate commitment to tackling racial inequalities in healthcare

- Provide community digital literacy support through targeted approaches using various mediums and languages matching patient needs. Options to receive digital devices should be offered to patients were needed

- Establish positive relationships through co-production research. Highlight minority ethnic patient experiences and ensure data is disaggregated to show ethnic groups and, where possible, age

- NHS England to mandate equality assessments (as recommended under the Public Sector Equality Duty) for services transitioning to digital modes to access impacts on minority ethnic groups

24 January 2024

Digital inclusion for parents, carers and families

Believe in children
Barnardo's

Barnardo's role in child health

Prevention and early intervention

Reducing child health inequalities

Filling the gaps in the pathway

Barnardo's works across the community, with health and education services to provide health and wellbeing services to children, young people and families.

Our services work across prevention, and early intervention, addressing the wider determinants of health and preventing families reaching crisis.

Barnardo's Consortium

Barnardo's is leading a consortium of 14 community and social enterprise groups working with diverse, minoritised or disadvantaged communities. Our Consortium brings a richness of lived experience from less heard communities into the heart of each of our projects.

Good Things Foundation highlighted a number of groups as most affected by digital exclusion:

- Low-income families with dependent children

- Black, Asian and mixed ethnicity communities

- People living in rural areas

- People experiencing complex lives and wider injustices

Reference
Good Things Foundation (2021) Digital exclusion and health inequalities

Online health information is regarded to offer speed and reassurance

In a focus group with parents, we asked about preferences in accessing information online and their views of online health related services. What parents/carers value most about online health related information:

- Speed – a fast way to health information, available 24/7
- Reassurance – GP appointments are regarded as 'hard to come by', therefore, online information allows for peace of mind in the non-urgent circumstances
- A first port of call – some use an online search as a first port of call for research prior to speaking with a professional

The most common topics parents searched for online:

- Weaning
- Teething
- Developmental stages
- General advice

Insights from our community partners shows access is being a major barrier for families from marginalised communities

We held two focus group sessions on digital inclusion and collated examples from our Consortium on their service users' experiences of digital exclusion.

- Access to devices and/or suitable internet connection is still a key barrier for families facing digital exclusion

- Community organisation are 'meeting people where they are' to increase digital inclusion, using familiar and trusted platforms to share culturally competent information. As a result, community organisations are seen as a source for information they can trust.

- Hybrid/blended offers are considered a key enabler to support families at risk of digital exclusion to access health information/services.

- Visual, audio and video resources can be more accessible than written test for those who need to access health information in different languages - translated information must be quality assured by native speakers.

- When parents/carers have what they need to access online information/services, they value the speed at which they can access information and the convenience of accessing information and services remotely.

Barnardo's Family Space

Believe in children
Barnardo's

Modelling our virtual family space

Tier 1
Universal open access website for parents and carers

2023

- 107,553 page views
- 49,000 users
- 96 pages
- 1850 videos viewed
- 1594 resources downloaded
- Hosted 2 public health campaigns

Barnardo's Virtual Family Space

Tier 2
Professional support online

Parents and carers register on platform to access facilitated courses, workshops, seminars and e-learning

Current offer:
- Best start in life pilots

Tier 3
1 to 1 targeted support

Parent and Carers book one to one appointments online

Current offer:
- Infant feeding 1:1 appointments
- Out of hours helpline

Barnardo's Tier 1 – Universal open-access website for parents and carers

Have you seen our Family Space?

For all stages of your parenting or caring journey

🔗 families.barnardos.org.uk

Barnardo's Family Space

virtualfamilyspace@barnardos.org.uk

Barnardo's Tier 2 – Professional support online

WELCOME TO BARNARDO'S VIRTUAL FAMILY SPACE

AVAILABLE

Understanding Your Baby

Understanding Your Baby is a six week course. We'll cover topics like your and your baby's feelings, your baby's brain development, communication and crying, behaviour patterns, developing a healthy sleep routine, feeding, play and development, and being apart from your baby.

Starting Solid Food

Starting Solid Food is a live 1.5 hour workshop. We'll cover topics like when and how to start introducing solid foods, food safety, allergies, gagging vs choking and commercial baby food.

Understanding Pregnancy, Labour, Birth and Your Baby

Understanding Pregnancy, Labour, Birth and Your Baby is a live online course made up of five workshops. We'll cover topics including your pregnancy journey and feelings, labour and birth, feeding and the partner's role.

Potty Training

Potty Training is a live workshop lasting up to two hours. We'll cover topics like preparing to use the potty and practising potty skills.

Sleep

Sleep is a live 1.5 hour workshop. We'll cover topics like safe sleep and creating sleep routines.

Five to Thrive

Five to Thrive is a live online course made up of four workshops. We'll cover topics like brain development and responding to your baby, the importance of touch and play, and talking with your baby.

Oral Health

Oral Health is a live workshop lasting up to two hours. We'll cover topics like diet, the impact of sugar on teeth, fluoride and oral hygiene.

Wellness Series by our Health Experts

Our health experts are running two workshops in the Wellness series, and you can attend just one, or both. They are: Understanding your baby's sleep and building a foundation of love: connecting with your baby.

COMING SOON

School Readiness

School Readiness is a pre-recorded online course with three workshops. We'll cover topics like preparing your child and family for starting school, plus what's involved with choosing a school.

Dads and Co-parents

Dads and Co-parents is a live online course with two workshops. We'll cover topics like supporting your partner, sleep routines, understanding your child's crying and development through play.
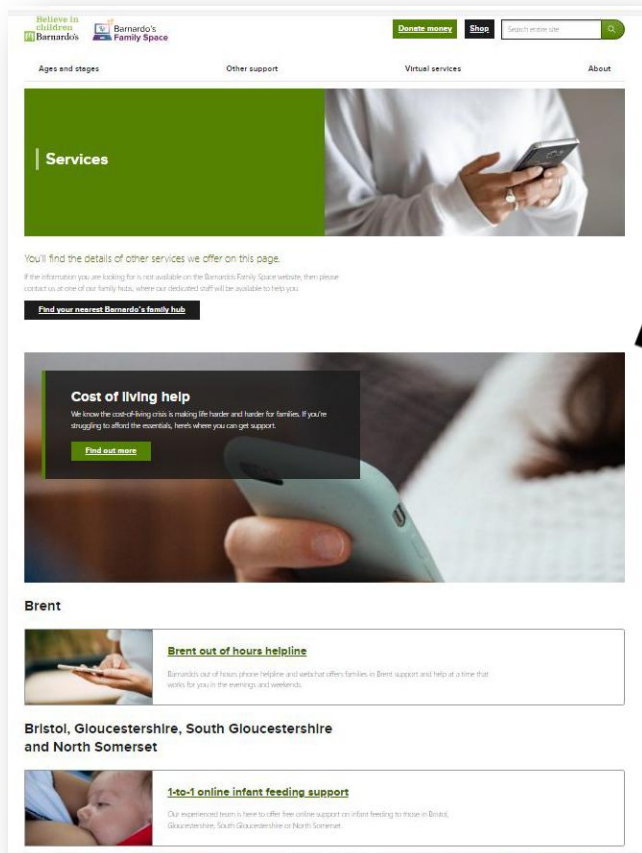
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The People's Postcode Lottery would like to thank all the players of the postcode lottery for their support

POSTCODE LOTTERY

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Barnardo's Tier 3 - 1:1 Virtual support.

- Bookable appointments
- Webchat
- Free phone number

Brent Out of Hours Family Support Line

Phone number: 0800 158 2358
Opening hours: **Saturday and Sunday: 10am – 5pm**
Monday, Wednesday, Friday: 6pm – 10pm

Barnardo's Gloucestershire and South Gloucestershire

Online Infant Feeding Support

Our experienced and friendly team will offer information and support to help you however you are feeding your baby.

We offer a free service to local families and provide:

- One to one online sessions with trained infant feeding practitioners.
- A non-judgmental friendly team and a safe, supportive space
- Assistance with any feeding questions or challenges you might have.
- Help finding further specialist support should you need it.
- Language translators on request.

This service is available Mon-Fri.

To book your video call or to view available time slots, please visit our website
families.barnardos.org.uk/services/infant-feeding
or scan the QR code below:

In case of technical difficulties where contact with an administrator is required you can call/text 07593 685617
or email GIFT@barnardos.org.uk

Please note this email/ number is not for feeding support.

Believe in children
Barnardo's

www.barnardos.org.uk
Barnardo's Registered Charity Nos.216250 and SC037605. 23799H22

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Sarah Trubody - Programme Manager
Karen Marlton - Team Manager

www.barnardos.org.uk   ⊡ f 🐦 @barnardos_uk

Believe in
children
Barnardo's

Seminar 2: Takeaways

Barriers that exclude people from digital health services, and how to remove them

Many of the barriers to digital inclusion are common to different groups (access, skills, confidence) - but take care to explore any differences for the specific groups you are looking to engage

Digital services can be useful - they can make services more accessible to those who may be otherwise excluded and can help with tracking of symptoms or treatments.

Think about staff and community support for your digital services - they may need training, resources, funding to make your service a success

Good Things Foundation

Q & A

Please submit questions in the chat panel.

Q&A Panel

Katie Heard
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c.hodge@hospiceuk.org

Jahan Foster Zabit
Race Equality Foundation
jahan@racefound.org.uk

Natalie Woods / Karen Marlton
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healthteam@barnardos.org.uk
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To help us understand the value of the seminars

1. How much knowledge do you now feel you have about digital inclusion and access to healthcare?

2. How capable do you now feel to identify ways to improve digital inclusion in healthcare?

Find out more: use our free resources to support you

Please check out our website or get in touch to find out more:

Web: www.goodthingsfoundation.org
Email: hello@goodthingsfoundation.org

Learn My Way (basic digital skills for life)
www.learnmyway.com

National Digital Inclusion Network:
www.goodthingsfoundation.org/network

National Databank:
www.goodthingsfoundation.org/national-databank

National Device Bank:
www.goodthingsfoundation.org/national-device-bank