SUITCEYES Scoping Report on Law and Policy on Deafblindness, Disability and New Technologies

Working Paper

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Contents

Executive Summary

This report discusses law and policy on new technologies: artificial intelligence (AI), machine learning and the Internet of Things (IoT) in relation to disabled people and people with deafblindness in the UK. Written as part of the SUITCEYES project, it provides a broad overview of formal rights and the extent to which disabled people can access new technologies in practice. The field is fast moving and volatile, with judgements regularly made and overturned in the courts and frequent new initiatives.

The UK government emphasises the importance of investing in new technologies as a means of strengthening the economy. The opportunities represented by technological developments have been largely welcomed by disabled people but there is not yet much discussion about how the technology might be used and developed by disabled people and people with deafblindness themselves, beyond a few specific projects.

People with Deafblindness

People with deafblindness are a relatively small and diverse group in the UK (estimated at 390,000 – 400,000 people). Two charities are their main representatives: Sense and Deafblind UK, which have sub -groups in England, Wales, Scotland and Northern Ireland. There is no national organisation run by deafblind people themselves. Single impairment organisations of and for people who are blind or Deaf, are larger, better funded and have more influence, but may not always address the specific priorities of people with deafblindness.

Local authorities in England and Wales have a statutory duty to make contact with and keep a record of all people with deafblindness, ensure that assessments of need for care and support are carried out and to provide appropriate services, trained personnel and accessible information. In Scotland, the British Sign Language (Scotland) Act 2015 has resulted in increased availability of sign language communication in the public sector and the law recognises people with deafblindness.

Beyond these specific measures, national laws on disability more generally, also apply to people with deafblindness.

Overview of Law and Policy on New Technologies and Disabled People: access and accessibility

National equality law requires that disabled people are not discriminated against in the provision of provision of goods, facilities and services, provision of health and care services, housing, exercise of public functions, premises, work, education, and associations. There is no absolute right to independent living in the UK, but political pressure applies in the form of the Convention on the Rights of Disabled People (CRPD) and its Optional Protocol, all of which the UK has signed and ratified. This is an important point of reference for service provision, housing, support and access to

technology and the UK, as with other country signatories, reports periodically on progress.

People with deafblindness and disabled people are disproportionately likely to be unemployed and living on a low income and for this reason, access to equipment via public funds is important. Services are funded through general taxation with some personal contributions by recipients for social care services, funded by local authorities. National Health Services (NHS) are free at the point of delivery.

Systems for allocating support, including technology, are complex and contested in the UK, especially for social care. Eligibility rules often vary with the size of the local authority budgets and there are frequent refusals and legal appeals. Although larger sums are available for household adaptations, expenditure on small items of equipment for personal use are more likely to be approved compared with larger items.

Digital accessibility laws apply in the UK, including several recent directives from the EU that have been incorporated into national law. However, the UK's exit from the EU means that the EU Accessibility Act will not automatically apply, due to a long transposition period that extends beyond December 2020.

Regulation of New Technologies

The UK government is collaborating with other national and international partners in the regulation of AI. However this is as yet underdeveloped and regulation lags behind development.

By way of example, use of personal cameras for face and object recognition is a contested issue in the UK. Some law enforcement organisations and security firms are permitted to use cameras for face recognition outdoors when authorised, and various regulations apply in other specific cases. Use of cameras and face and object recognition software as compensation for sight impairment is not legal at present. Similarly, the data processing that is involved must also be authorised, with appropriate and robust privacy safeguards for all involved.

The development of smart cities in the UK provides an opportunity to embed enabling technology in the environment, particularly useful for improving accessibility and reducing the amount of hardware that must be carried by people using wearables. As yet, such developments are scarce, although a few pilot projects aim to improve wayfinding in specific locations, such as along transport systems.

Ethics

The UK government has developed a strategy for AI and allocated funding and resources for development. The Centre for Data Ethics and Innovation was set up in July 2020 as part of the Department for Digital, Culture, Media & Sport, stating that its role is to advise the government about measures needed to ensure safe and ethical innovation in data and AI. Other national organisations include the AI Council

and the Office for AI. The Alan Turing Institute has been designated the lead body for AI research.

The UK government recognises that AI, machine learning and IoT can be discriminatory but very little attention as yet has been paid to the problems faced by disabled people. There is a tendency for governments to assume that developers will abide by existing legislation that will be sufficient to cover breaches. However this is clearly not always the case as several harmful practices involving targeting and surveillance have been recently identified. The opacity of AI is a problem for many seeking redress, who may be unaware of the potential harms involved.

Disabled People's Access to Information

No single source of information about new technologies is provided in the UK but a number of national and local government organisations, as well as third sector charities such as AbilityNet, Scope and others, routinely provide online information about new devices.

Access to information, especially about new developments, often depends on the degree to which disabled people are well connected to others, the extent to which they have digital access and the degree to which the information is accessible. Disabled people are four times more likely to be offline, (25% of disabled people; 3.5 million persons) as are almost a third of people over 60. This compares with 6% of the rest of the UK general population.

The Accessible Care Standard SCCI1605 requires that NHS and social care services provide information in accessible forms. The Care Quality Commission, the inspection body for National Health Service (NHS) and social care services asks about implementation of the standard by asking a small sample of service users to report on their experiences. While progress is reported in implementing the standard, there are still considerable problems, especially with information sharing between organisations.

Access to Equipment

The system for getting access to equipment is complex, with a number of different funding streams and eligibility requirements that vary over time.

Local authorities have a duty to provide services to those eligible. Disability equipment, telecare and home adaptations can be made available to support re-enablement and promote independence that contributes to preventing care and support needs. Equipment does not usually include complex technological devices but more basic items that may make everyday living easier are made available. For local authority funding, the broad aim is to improve independence, confidence and privacy: based on the Care Act 2014, personal wellbeing is taken into account as well as physical access. Generally, access to equipment is not easy to enforce through the law and local authorities have a considerable amount of discretion.

Certain types of equipment are also provided through the NHS. Similarly, separate funds for equipment are available to support disabled people in work and in education.

So far there has not been widespread inclusion of AI in the assistive technologies made available to disabled people through public funds. While direct payments may be used for small items of equipment as well as personal support, we were not able to find any information to confirm that disabled people were gaining access to new technologies in this way.

A number of private technology companies have collaborated with disability charities to develop pieces of equipment useful to disabled people. However barriers to accessing these remain and research shows that many blind people feel they are not making the most of new technology.

Accessibility measures in the built environment

General equality and accessibility laws apply to disabled people's access to the built environment. Accessibility and the built environment was reviewed by the House of Commons' Women and Equalities Committee in 2017, and this report pointed out a number of concerns and made significant recommendations for change. Some improvements have resulted from law and policy but substantial inequalities and lack of co-ordination remain.

The UK government has acknowledged of the potential for smart cities to enhance accessibility but many developments are at initial stages. There is not as yet a national level initiative but a number of city level measures exist in London, Bristol, Manchester and Edinburgh.

Skill Development and Work Opportunities

Disabled people are underrepresented in engineering and allied professions and most design professionals have limited experience of the needs of disabled people in relation to technology. Even where needs are correctly identified, the lived experience of using technology in practice in everyday life is often missing. Disabled people may be involved in testing but inclusion from the start is very rare.

This gap might be breached by increasing the number of disabled people entering the professions and by increased training of professionals in disability equality and awareness. The problem is recognised in the UK but there are very few specific measures in place to change the situation.

Similarly, social service personnel and other assessors for equipment often do not have adequate information about the potential or availability of AI and IoT equipment. Much equipment is in the early stages of development and may not be reliable enough to be used in everyday life. To date, there has been more use of AI by medical rather than other professionals dealing with disability equipment but it is important that gatekeepers are well informed about its potential.

Cybersecurity and Safeguards against hate crime and abuse

'Hate crime' is legally recognised in the UK and the term may be used to describe “a range of criminal behaviour where the perpetrator is motivated by hostility or demonstrates hostility towards the victim's disability, race, religion, sexual orientation or transgender identity.” It also applies to behaviour motivated by the *perceived* characteristics of the victim, whether or not they do have that characteristic. Because the perpetrator of a hate crime seeks to send a wider message to the community of people of which the victim is part, it is viewed as being more serious compared with similar crime that does not have this intention. Therefore, prosecutors may apply for an uplift, or increase, in the sentence for those convicted of a hate crime.

New technologies present many opportunities for abuse by perpetrators and for this reason it is important that safeguards are built in. The Alan Turing Institute has called for a new agenda of work in this area, including the responsible use of data – intensive technologies.

So far, the UK government has relied on companies to self – regulate but this is recognised to be ineffective in in dealing with harms to users. Regulation is planned, especially to combat harms to children and terrorism but it remains to be seen whether effective measures will be taken to safeguard disabled users who are disproportionately the target of hate and exploitation.

Main Report

1. People with Deafblindness

Although the UK government has jurisdiction over all four countries of the Union, certain powers are devolved to national assemblies of Scotland, Wales and Northern Ireland. The Westminster parliament serves as both the English and overall UK government. While there is often congruity between law and policies in the four countries and for some all are aligned, in recent years there has been increasing divergence with devolved matters. Where this divergence is marked, it is noted in this report.

1.1 Official recognition of people with deafblindness as an eligible group

Deafblindness is recognised by the UK government but in England this is mainly in relation to eligibility for services rather than accessibility, with a few exceptions. Accessibility needs are recognised to a greater extent in Scotland.

The terms ‘dual sensory loss’ and ‘multi-sensory impairment’ (MSI) are used in addition to deafblindness, often referring to different aspects of the impairment. MSI

is usually used in educational settings with children, to describe various sensory difficulties, including information processing difficulties with decoding and organising sensory messages.

A legal definition of deafblindness was developed by the Department of Health in 1995[1], as follows:

> 'A person is regarded as deafblind if their combined sight and hearing impairment cause difficulties with communication, access to information and mobility. This includes people with a progressive sight and hearing loss.'

In 2001 the UK Government introduced 'Deafblind Guidance' under Section 7 of the Local Authority Social Services Act 1970, giving new rights to people with deafblindness and bringing in new duties on Local Authorities to ensure their welfare. Further guidance for local authorities on how to provide care and support was issued in 2014.[2]

1.2 National data on people with deafblindness

Deafblind UK[3] estimates that there are nearly 400,000 deafblind people in the UK and expects an increase to over 600,000 by 2030, due to ageing of the population. Sense[4] estimates 390,000 with an increase to 600,000 by 2035. There are considerable difficulties establishing numbers because they rely on identifying all the people the definition applies to and because the population is very diverse. There is also little agreement about definitions,[5] adding complexity to the picture.The figures are therefore estimates.

The Department of Health guidance (2014) states that Clinical Commissioning Groups (local organisations that contract with health service providers) and local authorities should make sure that they identify and contact deafblind people in their areas, for example, by making comparisons with the numbers reported in other local authorities. However, to our knowledge these figures were not publicly available at the time of writing this report.

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[1] Department of Health (1995) *Think Dual Sensory*
[2] Department of Health (2014) *Care and Support for Deafblind Children and Adults Policy Guidance* https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/388198/Care_and_Support_for_Deafblind_Children_and_Adults_Policy_Guidance_12_12_14_FINAL.pdf
[3] Deafblind UK *What is Deafblindness?* https://deafblind.org.uk/information-advice/what-is-deafblindness/
[4] Sense *What is Deafblindness?* https://www.sense.org.uk/get-support/information-and-advice/conditions/deafblindness/
[5] Jaiswal, A., Aldersey, H., Wittich, W., Mirza, M. and Finlayson, M. (2018) Participation experiences of people with deafblindness or dual sensory loss: A scoping review of global deafblind literature. PLoS ONE 13(9): e0203772. https://doi.org/10.1371/journal.pone.0203772

Four distinct types of deafblindness are identified[6]: congenital, acquired, Usher syndrome and CHARGE. Congenital deafblindness describes impairments where children are born with sight or hearing loss or acquire sight or hearing loss before they develop language. Acquired deafblindness (the most frequent) is where sight and hearing impairment develops after language acquisition. An estimated 75% of all deafblind people are older people who have acquired deafblindness in later life.

Usher syndrome is a genetic condition associated with vision and hearing loss and three types are identified, depending on the onset and progression of the condition. SENSE suggests a prevalence rate of 15 per 100,000 people, which equates to 2,400 people for the UK population. CHARGE is believed to have a genetic origin and is associated with a range of physical impairments, including multisensory impairment. The number of people with CHARGE is not certain: research studies variously suggest a prevalence rate of 1 per 8,500 – 10,000 people, of which 60% are deafblind. This roughly equates to between 3,900 and 4,800 people in the UK. Again, it is important to point out that these are rough estimates.

1.3 National law and policies specific to people with deafblindness / sensory impairment

People with deafblindness are included in disability – related legislation and policy in the UK. Specific policies on deafblindness are quite limited.

In England, the difficulties faced by deafblind children and young people were recognised in 2009 by the Department of Health with the publication of '*Social Care for Deafblind Adults and Children*' (The Deafblind Guidance).[7] This placed important legal duties on all English local authorities to identify deafblind children living in the administrative area, to provide specialist assessments and to deliver support to meet the needs identified. Further rights are covered by more general legislation and policies on disabled people (see below) and the Deafblind Guidance was incorporated into the Care Act 2014.

British sign language was recognised by the Department for Work and Pensions (DWP) in 2003[8]. However this has not been extended to legal status for sign language or specific accessibility actions.

The British Sign Language (Scotland) Act 2015 aims to promote and facilitate the use and understanding of British Sign Language (BSL) in Scotland. The Scottish

[6] Wittich, W., Southall, K. Sikora, L. Watanabe, D.H. and Gagné, J-P (2013) 'What's in a name: Dual sensory impairment or deafblindness?.' *British Journal of Visual Impairment* 31(3): 198-207.
[7] Department of Health (2009) Series number LAC(DH) (2009) 6 Social Care for Deafblind Adults
[8] UK Government, Department of Work and Pensions, *Statement on British Sign Language* (2003) https://publications.parliament.uk/pa/cm200203/cmhansrd/vo030318/wmstext/30318m02.htm#:~:text=The%20Secretary%20of%20State%20for%20Work%20and%20Pensions%20(Mr.,for%20participation%20in%20everyday%20life.

parliament includes such matters as access to politics and public life as well as the receipt of services as priorities for implementing the Act. However, this again does not amount to formal recognition of BSL as a language because establishing this is a competence of the UK government rather than the Scottish parliament. Nevertheless, it means that Scottish law and policy on language is more extensive compared with other parts of the UK. Public authorities are required to publish plans that include steps they will to take in regard to BSL. Importantly, Deafblind Scotland was able to ensure that tactile sign language was included in the Bill.[9] .

However, some shortcomings have been identified[10]. Members of the Scottish Parliament (MSPs) consulted more widely with organisations *for* people using sign language rather than with people who use sign language themselves. Consequently, Deaf – led organisations have lacked a voice in policy development and opportunities for direct consultation with sign language users have been quite limited. These shortcomings are noted in the government's 2020 plan, which include a number of actions relating to involvement for BSL users.

1.4 Important bodies that represent, report on or have responsibility for people with deafblindness

Two charities in the UK are concerned with deafblind people. Deafblind UK[11] and Sense[12] are both based in England and each has teams in the other three countries of the UK: Scotland, Wales and Northern Ireland, as well as local organisations. They both provide services and support directly to people with deafblindness and their families, including residential housing, individual support, advocacy and advice. Sense provides day centre facilities in three locations.

There is no dedicated user – led organisation of people with deafblindness in the UK.

Organisations that represent people who are either blind or Deaf, campaign actively. The Royal National Society of Blind People (RNIB)[13], developed from the Royal National Society for the Blind and has national sub-offices.

The British Deaf Association (BDA)[14] is the largest organisation representing Deaf people in the UK. A number of others exist, as do organisations that aim to support and assist Deaf people specifically.

[9] See Scottish Government: *British Sign Language (BSL): National Plan 2017 to 2023* https://www.gov.scot/publications/british-sign-language-bsl-national-plan-2017-2023/pages/2/
[10] See de Meulder, M., Murray, J.J. and McKee, R.L. (2019) *The Legal Recognition of Sign Languages: advocacy and outcomes around the world,* Multilingual Matters ISBN 9781788923996
[11] Deafblind UK https://deafblind.org.uk/
[12] Sense UK https://www.sense.org.uk/
[13] RNIB https://www.rnib.org.uk/
[14] BDA https://bda.org.uk/

2. Overview of Law and Policy on New Technologies and Disabled People

2.1 Overall legal and policy framework for access to technology

All parts of the UK are party to international treaties and in this context, notably the Convention on the Rights of Persons with Disabilities (CRPD). Several Articles set out rights to accessible technology, for example, in Article 9: Accessibility. Article 19: Living independently and being included in the community, is especially clear about support to live in the community and not in institutions. The provisions of the CRPD are made more binding through the additional signing and ratification of the Optional Protocol. The UK government has signed and ratified all parts of the Convention.

The Equality Act 2010 prohibits discrimination against certain groups of people designated as having 'protected characteristics'[15] . Six groups of people are identified, on the basis of disability as well as gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation. The legislation provides the legal basis for equality and non-discrimination in most of the UK: England, Scotland and Wales. In Northern Ireland the Equality Act is not in force and the relevant law for disability is the Disability Discrimination Act 1995, which covered all of the UK prior to 2010.[16]

Section 6 of the Equality Act 2010 states:

> A person (P) has a disability if—
> (a) P has a physical or mental impairment, and
> (b) the impairment has a substantial and long-term adverse effect on P's ability to carry out normal day-to-day activities."

Definitions of disability are not always straightforward in practice however, because eligibility may vary according to the available resources, determined differently depending on the funding stream and geographical area.

The Equality Act 2010 provides protection from discrimination in a variety of circumstances, which include the provision of goods, facilities and services, provision of health and care services, housing, exercise of public functions, premises, work, education, and associations. Protection is also extended to others who may be discriminated against because they are associated with a person with a protected

[15] Equality Act 2010, s 4 http://www.legislation.gov.uk/ukpga/2010/15/section/4
[16] Equality Commission for Northern Ireland https://www.equalityni.org/Legislation

characteristic (such as family members). The Public Sector Equality Duty sets out further obligations for public bodies.[17]

The Equality and Human Rights Commission has responsibility for enforcement of the Equality Act, with the associated national bodies in Wales, Scotland and Northern Ireland.[18]

The Equality Act 2010 is important for underpinning rights to technology and other support to individuals and also for providing the basis for national accessibility law. Other laws govern individuals' rights to actually receive and use items of personal equipment and technology, notably the Care Act 2014.[19]

The Care Act 2014 aimed to bring together a complex range of legislation and policy to provide the legal framework for eligibility to support and assistance. Related policy documents include the Care and Support (Charging and Assessment of Resources) Regulations 2014[20], the Care and Support (Eligibility Criteria) Regulations 2015[21] and the Care and the Support Statutory Guidance.[22] Access to health and social care is a devolved matter and in theory, different courses of action may be followed by different governments. In practice, provisions are broadly similar.

Under the provisions of the Care Act, local authorities must undertake an assessment for any adult who appears to have needs for care and support and they have a duty to provide support if the needs are eligible. Care and support include equipment and adaptations to the home.

The Care Act 2014 has however, been weakened by the Coronavirus Act 2020. This more recent law removes the duty from local authorities in England to assess and meet disabled people's social care needs, replacing it with a power to do so. While it is understandable that in the course of a pandemic local services may be over-burdened with demands, the result is to substantially disadvantage disabled people and their rights to access support and technology. The results of this are not all evident at the time of writing this report but are likely to become more apparent in the coming months.

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[17] Public Sector Equality Duty https://www.equalityhumanrights.com/en/advice-and-guidance/public-sector-equality-duty

[18] EHRC (2019) *Our litigation and enforcement policy 2019-22* https://www.equalityhumanrights.com/sites/default/files/our-litigation-and-enforcement-policy-2019-2022.pdf

[19] Care Act 2014 http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted; Deafblind UK https://deafblind.org.uk/information-advice/deafblind-assessments/understanding-your-legal-rights-the-care-act-2014/

[20] Care and Support (Charging and Assessment of Resources) Regulations 2014 https://www.legislation.gov.uk/uksi/2014/2672/contents/made

[21] Care and Support (Eligibility Criteria) Regulations 2015 https://www.legislation.gov.uk/uksi/2015/313/contents/made

[22] Department of Health and Social Care**.** *Care and support statutory guidance: Updated 24 June 2020* https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance

2.2 Overall legal and policy framework for accessibility

The Equality Act 2010 imposes an anticipatory duty of reasonable adjustment in relation to disabled people. This is an obligation to remove the disadvantage caused by a practice, physical feature or requirement where it exists in comparison to conditions for a non-disabled person.[23] The anticipatory duty is a key feature of the Act and it supports accessibility in general, rather than adjustments to allow an individual to participate.

All NHS and social care providers must follow the Accessible Care Standard.[24] This requires all publicly funded adult social care and health services to identify and meet the information and communication needs of service users. Providers must identify people, record their requirements, use a flagging system, share information appropriately and meet needs. Therefore, it is a pre-requisite for disabled people obtaining personally useful technology that is supplied through these channels.

European directives have been implemented in the UK in a similar way to other Member States. The Communications Act 2003[25] set up Ofcom as regulator for telecommunications and it refers to the need to ensure participation of disabled people. Such rights are loosely worded however, and many sections ask providers and authorities to 'make arrangements' for disabled people, to the greatest extent possible, rather than requiring specific actions to be taken.

Several recent EU directives that have relevance for disabled and deafblind people have been implemented in the UK.

The Public Sector Bodies (Websites and Mobile Applications) (No. 2) Accessibility Regulations 2018[26] legislate for digital accessibility, transposing EU Directive 2016/2102 into UK law. The UK government provides guidance on implementing the law[27] and the arrangements for enforcement are explained[28]. It should be noted that there are provisions for exceptions and organisations do not need to make accessibility arrangements if doing so would constitute a 'disproportionate burden'. Several disabled people's organisations have expressed concern that this caveat may be over-used, resulting in exclusion for many potential users.

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[23] http://www.legislation.gov.uk/ukpga/2010/15/section/20

[24] Accessible Care Standard https://www.sense.org.uk/get-support/information-and-advice/accessible-information-standard/

[25] Communications Act, 2003 https://www.legislation.gov.uk/ukpga/2003/21/contents

[26] Public Sector Bodies (Websites and Mobile Applications) (No. 2) Accessibility Regulations 2018 http://www.legislation.gov.uk/uksi/2018/952/made

[27] UK Government, *Understanding accessibility requirements for public sector bodies* https://www.gov.uk/guidance/accessibility-requirements-for-public-sector-websites-and-apps

[28] A sample of websites is examined each year by the Government Digital Service

GDPR regulations also apply in the UK. The UK Data Protection Act incorporates the EU GDPR into national law[29], so the requirement remains in place after Brexit.

The Directive (EU) 2018/1972 on the European Electronic Communications Code (Recast) (EECC) [30] enters into force on the 20 December 2020 and has a deadline of December 21 2020 for transposition. The UK government has indicated that it plans to implement the measures by the same timeframe despite some delay due to the coronavirus pandemic[31]. The regulator, Ofcom, has consulted on implementation[32] and a final statement is expected in autumn 2020. Measures for ensuring equality for disabled people are included as for the European legislation.

Although laws and policies on accessibility are aligned between the UK and Europe, Brexit may disrupt this after December 2020. The Audiovisual Media Services Directive falls within the transition period before Brexit, with implementation required by September 2020.[33] This should result in improved accessibility for disabled people.

Not all EU law in progress is likely to become law in the UK. Following Brexit, the Accessibility Act[34] is unlikely to be incorporated, due to the long period allowed for implementation. The Accessibility Act allows the creation of a level playing field for good and services and similar standards across Europe allow disabled people to use technology across borders. It remains to be seen whether trading arrangements will lend impetus to common standards with Europe but there does not appear to be impetus within the UK Government to implement the Act or to develop a UK version.[35]

Although not a technical standard, the BS8878 code of practice[36] gives guidance and recommendations for embedding accessibility into projects. It outlines ways to define and assess the impact of web products on users, especially for disabled and older people. User needs are discussed, highlighting those of people with physical impairments or learning difficulties.

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[29] UK Government, *Data Protection* https://www.gov.uk/data-protection
[30] https://eur-lex.europa.eu/legal-content/EN/TXT/?qid=1546528074374&uri=CELEX:32018L1972
[31] Government response to the public consultation on implementing the European Electronic Communications Code https://www.gov.uk/government/consultations/implementing-the-european-electronic-communications-code
[32] Ofcom (2020) Implementing the new European Electronic Communications Code https://www.ofcom.org.uk/__data/assets/pdf_file/0033/198933/consultation-eecc-revised-proposals.pdf
[33] The Audiovisual Media Services Regulations 2020, https://www.legislation.gov.uk/uksi/2020/1062/pdfs/uksi_20201062_en.pdf
[34] European Accessibility Act: Directive (EU) 2019/882 of the European Parliament and of the Council of 17 April 2019 https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=COM%3A2015%3A0615%3AFIN
[35] See Cabinet Office communications http://europeanmemoranda.cabinetoffice.gov.uk/memorandum/proposal-for-directive-of-the-ep-council-on-the-approximation-of-the-laws-regulations-administrative
[36] British Standards Institute S8878 https://shop.bsigroup.com/en/ProductDetail/?pid=000000000030180388&rdt=wmt

This section has noted some of the main legal and policy measures on accessibility, bearing in mind people with deafblindness and sensory impairments. There have been recent advances in legislation and other measures but substantial implementation problems remain and there are also differences between the UK countries.

3. Regulation of New Technologies

Use of new technologies is expanding rapidly in the UK, as in other European countries, but regulation lags behind. However, regulation has a high profile, with rights to personal privacy versus surveillance the focus of attention. Currently there is a rather piecemeal approach to regulation, which is often tied to particular sectors and uses.

New regulations are likely, with the UK government identifying a number of actions that need to be taken. For example, the All Party Parliamentary Group on Data Analytics[37] has proposed a 'right to know' and 'public good test' in the context of a regulatory framework and official oversight. Other Parliamentary groups such as the All – Party Parliamentary Group on Assistive Technology, among others, has put forward similar recommendations.

There is no dedicated regulation of technology that compensates for sensory impairment and the fit between currently permitted use and areas of potential use by disabled people is rather poor. This may be illustrated by the regulation of personal cameras for object and face recognition, which is an important requirement for the SUITCEYES HIPI wearable. By way of example, the rest of this section discusses those issues in more detail.

Use of personal cameras and sensors

Use of cameras is governed by the GDPR and UK Data Protection Act 2018[38] (which incorporates the GDPR into UK law). Close circuit TV (CCTV) is permitted on private property and provided no data is captured from beyond property boundaries, data protection legislation does not apply. People who are filmed have several rights, including: the right to know that that CCTV is being used (usually done through providing signs), the right to know what information is being held[39] and the right to ask for a copy of the information. People being filmed may also ask for CCTV users to desist in future.

In the UK, the use of face recognition is highly contested, both in terms of the gathering of general data and for the purposes of criminal investigation. At times these purposes can be blurred, as when used for crowd surveillance. An important

[37] All – Party Group on Data Analytics https://www.policyconnect.org.uk/appgda/research/trust-transparency-and-technology-building-data-policies-public-good
[38] Data Protection Act 2018 https://www.legislation.gov.uk/ukpga/2018/12/contents/enacted
[39] ICO, https://ico.org.uk/your-data-matters/

legal judgement supported use of live face recognition by the police in South Wales[40] as part of a pilot programme sponsored by the Home Office. However, an appeal launched by Liberty, a national human rights organisation, has been successful in challenging this, on the basis that "South Wales Police had failed to adequately take account of the discriminatory impact of facial recognition technology, and had failed to meet its obligations under equality laws."[41] Liberty is campaigning for use of the technology to be banned.

Questions have also arisen regarding whether photography potentially contravenes GDPR and the Data Protection Act 2018. Taking photographs of people who are anonymised does not in and of itself contravene the legislation but if images are stored alongside personal information or other identifiers, GDPR does apply.

The law on recording sound is less stringent and it is not illegal in the UK to record a conversation without consent.

Bodycams are often used by law enforcement officers and the security industry, in situations where they are protecting property or ensuring compliance with the law. More leeway is accorded here, compared with use of CCTV. Users of personal cameras may need to apply for a Security Industry licence[42] and the license must be worn and clearly visible at all times. The Security Industry Authority has responsibility for regulating the private security industry under the Private Security Industry Act 2001.[43]

From the point of view of disabled people wishing to use person and object recognition software, the whole point of using cameras and sensors is to identify the people concerned. However this use is not at present legally recognised and other legally permitted exemptions to the law do not fit well.

Clearly some more explicit recognition, based on the fact that use of the technology is compensation for sensory and / or information processing impairment is necessary. This should also strengthen the argument in favour of ownership of the data by disabled people themselves, with support as needed.

Handling and ownership of data

The Data Protection Act 2018 is based on the GDPR and it distinguishes between personal data, which is "any information relating to an identified or identifiable living individual"[44], and the processing of data related to criminal acts. Protections are

[40] R -v- The Chief Constable of South Wales Police and others https://www.judiciary.uk/judgments/r-v-the-chief-constable-of-south-wales-police-and-others/
[41] Liberty wins ground – breaking victory against facial recognition tech, https://www.libertyhumanrights.org.uk/issue/liberty-wins-ground-breaking-victory-against-facial-recognition-tech/
[42] Security Industry Authority https://www.sia.homeoffice.gov.uk/Pages/licensing-applicants.aspx
[43] Private Security Industry Act 2001 https://www.legislation.gov.uk/ukpga/2001/12/contents
[44] Data Protection Act 2018, Section 3(2)

stronger for personal data. Other distinctions are made between data subjects, and controllers and processors of data.

In handling information, 'data protection principles' must be followed. These state that for people handling personal data:

> "They must make sure the information is:
> - used fairly, lawfully and transparently
> - used for specified, explicit purposes
> - used in a way that is adequate, relevant and limited to only what is necessary
> - accurate and, where necessary, kept up to date
> - kept for no longer than is necessary
> - handled in a way that ensures appropriate security, including protection against unlawful or unauthorised processing, access, loss, destruction or damage.[45]"

The Data Protection Act 2018 designates some data as falling into "special categories", which include race and ethnicity, political opinions, religious or philosophical beliefs, trade union membership, biometric data, health, sex life and sexual orientation. Information about disability or impairment is included to the extent that it is linked to health information.

Recent increases in data transfers are important to the economy. From the perspective of the UK, the ICO points out the need to comply with both EU and UK law at the end of the transition period. At the time of writing this report, many issues are unresolved. The ICO has produced a guide[46] to the sharing of personal data between organisations. They note that the guide has not been updated since the Data Protection Act 2018 and that further work on this will be carried out.

Because of the sensitivity of data handling issues, it is likely that some special arrangements will be needed with regard to the legality of data processing by people with sensory and cognitive impairments. As yet, there appears that little work on this specifically has been done to date, beyond an increasing recognition of the importance of involving disabled people in the early stages of product design. However further policy initiatives are needed if people with sensory impairments are to make use of new technological developments and have access to needed information. The EU Article 29 Data Protection Working Party has recognised the potential of biometric data for enhancing participation[47], within a human rights framework, pointing to the need to avoid stigmatisation. This recognition is important

[45] UK Government, *Data Protection* https://www.gov.uk/data-protection

[46] ICO Data Sharing Code of Practice https://ico.org.uk/media/for-organisations/documents/1068/data_sharing_code_of_practice.pdf

[47] EU Article 29 Data Protection Working Party (2012) Opinion 3/2012 on developments in biometric technologies https://ec.europa.eu/justice/article-29/documentation/opinion-recommendation/files/2012/wp193_en.pdf

but it is not fully recognised in UK policy, where disabled people are often still regarded as data subjects rather than controllers or processors.

The Brave Report[48] has questioned the extent to which European governments are adequately enforcing the GDPR. They note that Article 52(4) of the GPDR requires that national governments to give data protection agencies the human and financial resources required to perform their work. In the UK, however, it is noted that only 3% of ICO's 650 staff focus on technology privacy, suggesting that this is not adequate for effectiveness.

In summary, government commitments to data protection are contested and under-resourced and enforcement still lags behind technical developments.

4. Ethical frameworks relevant to disabled people and new technologies in place or under development

The UK has developed a strategy for the development of AI and allocated funding and resources for development. As part of this, the Centre for Data Ethics and Innovation was set up in July 2020 under the Department for Digital, Culture, Media and Sport[49]. Other organisations with a related brief include the AI Council[50] and the Office for AI[51].

The Centre describes its role as advising government about measures needed to ensure safe and ethical innovation in data and AI. It is not a regulator, but aims to help ensure that those who govern and regulate the use of data across sectors do so effectively. At the time or writing this report, a number of publications had been produced, including a report concerned with bias in algorithmic decision making.[52] The report points out some well-known examples of discrimination based on race and gender but does not have any comment on disability beyond mention as a protected characteristic.

[48] Brave Report (2020) https://brave.com/wp-content/uploads/2020/04/Brave-2020-DPA-Report.pdf
[49] Centre for Data Ethics and Innovation https://www.gov.uk/government/organisations/centre-for-data-ethics-and-innovation
[50] UK Government *AI Council* https://www.gov.uk/government/groups/ai-council#membership
[51] Office for AI: https://www.gov.uk/government/organisations/office-for-artificial-intelligence
[52] Centre for Data Ethics and Innovation *Review on bias in algorithmic decision making* (2019) https://www.gov.uk/government/publications/the-centre-for-data-ethics-and-innovation-calls-for-evidence-on-online-targeting-and-bias-in-algorithmic-decision-making/centre-for-data-ethics-and-innovation-review-on-bias-in-algorithmic-decision-making

The government has also published guidance for public sector AI developers on making AI relevant to users.[53] The Data Ethics Framework[54], for example, provides guidance for government on transparency, accountability and fairness. Specific actions include a focus on public benefit and user need, including attention to human rights and the unintended consequences of carrying out projects involving AI. Again, the emphasis is on self-monitoring by the initiators of projects rather than monitoring by government or its agencies. This approach is based on a more detailed report[55] prepared by the Alan Turing Institute, which has been designated by the UK government as the lead body for AI research.

The Institute has addressed the issue of disability in the context of inclusion, through outlining some general ethical principles and sponsoring some projects around the theme of accessibility[56]. A more specific programme of work has yet to be developed.[57]

The UK government recognises that AI, machine learning and IoT can be discriminatory but very little attention as yet has been paid to the problems faced by disabled people. There is no evidence that the omission of disability is deliberate in reports, which tend to be responsive to some specific issues such as reports of financial discrimination against people from minority ethnic groups and employment discrimination against women. However, with omission and discrimination a continuing problem for disabled people it is notable that safeguards have not been developed.

A study from the search engine Brave in 2020[58] uncovered widespread surveillance of UK citizens by private companies embedded on UK council websites. The report highlights that people seeking help for addiction, disability, and poverty on council websites were specifically targeted. There is a tendency for governments to assume that developers will abide by existing legislation that will be sufficient to cover breaches. However this is clearly not always the case and the opacity of AI is a problem for many seeking redress, who may be unaware of the harms involved. As yet there is not much attempt to ensure the accountability of private sector organisations.

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[53] See for example: Data Ethics Framework: https://www.gov.uk/government/publications/data-ethics-framework/data-ethics-framework-2020; Guidelines for AI procurement: https://www.gov.uk/government/publications/guidelines-for-ai-procurement/guidelines-for-ai-procurement

[54] Data Ethics Framework https://www.gov.uk/government/publications/data-ethics-framework/data-ethics-framework-2020

[55] Leslie, D. (2019). Understanding artificial intelligence ethics and safety: A guide for the responsible design and implementation of AI systems in the public sector. The Alan Turing Institute. https://doi.org/10.5281/zenodo.3240529

[56] Alan Turing Institute, AI and Inclusion https://www.turing.ac.uk/research/research-projects/ai-and-inclusion

[57] Alan Turing Institute Challenges to Implementation of AI and inclusion, https://www.emptech.info/wp/2019/10/17/challenges-to-implementation-of-ai-and-inclusion/

[58] Brave https://brave.com/wp-content/uploads/2020/02/Surveillance-on-UK-council-websites_compressed_version.pdf

This limited progress has been acknowledged by the Committee on Standards in Public Life (CSPL)[59], an advisory non-departmental public body of the UK Government that advises the Prime Minister on ethical standards of public life. The Committee considers current arrangements unclear and inadequate and a number of recommendations are made to bring in greater regulation and accountability of AI, especially in relation to ethics and bias.

5. Disabled People's Access to Information

Access to information about technology is not centralised in the UK and the DARE index notes that there is no officially required process for involving disabled people in policy-making for the development of technology. However, a number of national and local government organisations, as well as third sector charities such as AbilityNet[60], Scope[61] and others, routinely provide information about new developments. For this reason, access to information, especially about new developments, may depend on the degree to which disabled people are well connected to others, have digital access and the information is accessible.

For people with deafblindness, Sense[62] provides information about potentially useful technology and Deafblind UK[63] lists a number of useful apps for communication.

With information on technology mostly available online, lack of digital access can be very problematic. Recent research shows that inequalities persist. The Office for National Statistics (ONS)[64] reports in 2019 that although the number of 'internet non-users' has been declining over time and nearly halving since 2011, in 2018, 5.3 million adults in the UK (10.0% of the adult UK population) were still non-users. Beyond simple access, digital skills are necessary. The Tech Partnership Basic Digital Skills framework describes five basic skills and activities for effective use of the internet.[65] ONS research shows that there has been no improvement and skill levels have remained unchanged in recent years.

The UK Consumer Digital Index 2018 reports that disabled people are four times more likely to be offline (25% of disabled people; 3.5 million persons), as are almost

[59] Committee for Standards in Public Life (2020) *Artificial Intelligence and Public Standards: A Review by the Committee on Standards in Public Life* https://www.gov.uk/government/publications/artificial-intelligence-and-public-standards-report
[60] AbilityNet https://abilitynet.org.uk/about-abilitynet
[61] Scope https://www.scope.org.uk/news-and-stories/artificial-intelligence-disabled-people/
[62] Sense, *Technology at Sense* https://www.sense.org.uk/get-support/information-and-advice/technology/technology-at-sense/
[63] Deafblind UK https://deafblind.org.uk/information-advice/technology/
[64] ONS (2019) *Exploring the UK's digital divide* https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/articles/exploringtheuksdigitaldivide/2019-03-04
[65] See for more details: Department of Education (2019) *Essential digital skills framework* https://www.gov.uk/government/publications/essential-digital-skills-framework/essential-digital-skills-framework

a third of people over 60,[66] compared with 6% of the rest of the UK population. Disabled people also disproportionately report (25%) lack of interest, knowledge and motivation for using the internet. It follows that relevant support and instruction to use technology as well as access to it are needed.

While these differences are large, it is also important to note that they are likely to be an under-estimate. The study only counted people who are officially registered as disabled and this number is smaller than that of all people with impairments. Many people may be legally disabled under the definitions of UK legislation but may not consider or report themselves to be so, often because of discrimination.

Another important source of information is through social care organisations. As noted in Section 2.2, the Accessible Care Standard SCCI1605 requires that NHS and social care services provide information in accessible forms. The Care Quality Commission, the inspection body for NHS and social care services, regularly investigates implementation of the standard by asking a small sample of service users to report on their experiences.[67] Their 2018-9 report[68] found that despite progress, considerable implementation problems remain, especially with information sharing between organisations. The CQC also noted several shortcomings. 59% of trusts that answered a question about this, said they offered accessible appointment letters (104 of 177 trusts). Asking service users, 33% of people who responded said they were given easy to read information on how to make a complaint (207 of 634 people from 119 trusts). Finally, the emphasis of the Accessibility Standard is on meeting service users' various information needs, through a range of formats. The Standard states:

> "Accessible Information aims to ensure that people with a disability, impairment or sensory loss get information about their health and care which they can read and understand (for example in easy read, braille or via email) and communication support if they need it (for example British Sign Language (BSL) interpretation)".[69]

However the CQC evaluation report only discusses the ways that information has been made accessible for people with learning difficulties. There is no mention of people with sensory impairments or whether alternative formats are available.

[66] Lloyds Bank (2019) *UK Consumer Digital Index 2018*, https://www.lloydsbank.com/assets/media/pdfs/banking_with_us/whats-happening/LB-Consumer-Digital-Index-2018-Report.pdf

[67] Care Quality Commission https://www.cqc.org.uk/guidance-providers/meeting-accessible-information-standard

[68] Care Quality Commission (2019) *The state of health care and adult social care in England 2018/19* https://www.cqc.org.uk/sites/default/files/20191015b_stateofcare1819_fullreport.pdf

[69] SCCI1605 Accessible Information Clinical Safety Case p10 https://www.england.nhs.uk/ourwork/accessibleinfo/background/

Research by the Royal National Institute of Blind People (RNIB) also indicates that access to information in general is still very sporadic.[70]

In summary, although in theory there are many more opportunities for disabled people to gain information about new technology and its potential for improved quality of life, in practice, there are significant shortcomings.

6. Access to Equipment

Equipment is made available to disabled people through the public sector, through a range of public services and providers. This section gives an overview of this and considers the extent to which new technologies such as AI are included. Technology available directly from the private sector is also discussed.

While arrangements are similar in the four UK countries, the administration of these is devolved to the four governments. The situation in England is discussed by way of example.

6.1 Public Sector

The system for securing equipment is complex, as funding and procedures vary according to eligibility thresholds, where equipment is used and its purpose. Relevant UK policy measures include: the Care and Support (Charging and Assessment of Resources) Regulations 2014,[71] the Care and Support (Eligibility Criteria) Regulations 2015[72] and the Care and Support Statutory Guidance.[73] Ofcom, the communications regulator, reports on disabled people's access to and use of communications devices compared with the general population.[74]

For home – based aids and equipment, there are important distinctions in the definitions of 'equipment', 'minor adaptations' and 'major adaptations', and the funding rules and processes for accessing them are different for each.[75] Small items of equipment for use in daily living and minor adaptations to accommodation are

[70] Royal National Institute of Blind People (RNIB) https://www.rnib.org.uk/rnibconnect/news/my-voice-research
[71] Care and Support (Charging and Assessment of Resources) Regulations https://www.legislation.gov.uk/uksi/2014/2672/pdfs/uksi_20142672_en.pdf
[72] Care and Support (Eligibility Criteria) Regulations 2015https://www.legislation.gov.uk/uksi/2015/313/pdfs/uksi_20150313_en.pdf
[73] Care and Support Statutory Guidance https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance
[74] Ofcom Disabled consumers' access and use of communications services https://www.ofcom.org.uk/research-and-data/multi-sector-research/accessibility-research/disabled-consumers-ownership-comms-services
[75] For more details see: Equality and Human Rights Commission (2018*) Your rights to accessible and adaptable housing in England A guide for disabled people and the organisations that support them* https://www.equalityhumanrights.com/sites/default/files/housing-and-disabled-people-your-rights-england_0.pdf

usually obtained through local social service departments.[76] They have a duty to provide services to prevent, reduce, and delay support needs and the guidance recognises that disability equipment, telecare and home adaptations can support re-enablement and promote independence. Items generally do not include complex technological devices but more basic items that may make everyday living easier.

For local authorities, the broad aim is to improve independence, confidence and privacy: based on the Care Act 2014, personal wellbeing is taken into account as well as physical access. Access to equipment is not easy to enforce through the law and local authorities have a considerable amount of discretion.[77] Provision is driven by cost as well as need and as noted previously, existing rights to access equipment have been weakened during the coronavirus pandemic.

Devices are usually recommended by an occupational therapist (OT) or other professional following an assessment of needs. During that process, applicants should agree with the local authority who owns the equipment, who is responsible for its continuing care and maintenance, and how these costs are to be met. Direct payments (funding rather than services given to the disabled applicant to arrange the assistance they are assessed as needing) may be used to meet any eligible needs and this may include specialist equipment or small home adaptations.

Local authorities have the power to charge applicants for services or equipment. However, equipment and small adaptations that cost £1,000 or less must be provided free of charge, providing it is agreed that this is part of meeting the needs of the applicant. They also may not charge for a service that involves provision of disability equipment or minor adaptations related to nursing at home or aids for daily living.

There are about 40 Equipment Demonstration Centres across the UK with a wide range of equipment and staff to give advice. At the time of writing this report however, many did not appear to be open for consultation, due to lockdown measures.

Certain kinds of devices are also funded or prescribed by NHS health authorities, including wheelchairs and low vision aids.

Larger adaptations to housing are available through Disabled Facilities Grants[78]. These involve more expensive and extensive adaptations and are means tested. Arrangements are carried out in conjunction with the housing department or district housing authority.

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[76] NHS Household gadgets and equipment to make life easier https://www.nhs.uk/conditions/social-care-and-support-guide/care-services-equipment-and-care-homes/household-gadgets-and-equipment-to-make-life-easier/

[77] For more details see: Mandelstam, M. (2015) Home Adaptations: The Care Act 2014 and related provision across the United Kingdom, https://www.rcot.co.uk/sites/default/files/Home-adaptations-Care-Act2014.pdf

[78] Disabled Facilities Grants https://www.gov.uk/disabled-facilities-grants

Equipment for use at work is funded by the Access to Work scheme.[79] This may be used to pay for specialist equipment as well as travel if the applicant cannot use public transport, a support worker or job coach to help at work and a communicator at a job interview.

Support for learning in school or college may be funded by special educational needs and disability budgets.[80]

Use of AI and other new technologies in the provision of equipment is still limited. Of all options, robots have attracted most attention. Recently it has been reported that robots will be deployed in care homes,[81] but they do not appear to be available yet outside institutional settings. This use may be driven at least in part by cost and expediency as there is currently a care staff shortage in care homes in the UK. To our knowledge, there are no instances of robots being made available for individual disabled people to support living in the community.

There are reports of lengthy delays for assessments by occupational therapists and for Disabled Facilities Grants. Although officially applicants should not have to wait an unreasonable amount of time, there is no time limit set for this.

6.2 Private Sector

Sense[82] and other charities such as Age UK provide information about an increasing number of apps, alternative and augmentative communication devices, computing aids and other devices that can assist disabled people in everyday life. Access to free or low cost apps can be a much quicker alternative to sometimes cumbersome and difficult processes of securing assistive technology through public services.

The UK Government states that the AI sector has agreed a £1 billion package of support from government and industry to boost the development of new technology. As mentioned above, the government Office for Artificial Intelligence has been established and an AI strategy developed. However, at this level there is little mention of disabled people or reference to equality issues. The Alan Turing Institute has taken the most initiative, with a strand of work on AI and inclusion but this is not carried across the policy sector.[83]

Many private companies advertise disability equipment through websites, mail order catalogues, shops or showrooms. Some larger chemists stock small items of equipment or have mail order catalogues. The national charity Disabled Living

[79] Access to Work https://www.gov.uk/access-to-work
[80] Disabled Student's Allowance https://www.gov.uk/disabled-students-allowances-dsas
[81] The Guardian (7.9.20) Robots to be used in UK care homes to help reduce loneliness https://www.theguardian.com/society/2020/sep/07/robots-used-uk-care-homes-help-reduce-loneliness#:~:text=4%2C034,mental%20health%20and%20reduced%20loneliness
[82] Sense
[83] Alan Turing Institute https://www.turing.ac.uk/research/research-projects/ai-and-inclusion

Foundation provides information about a wide range of equipment via the Living Made Easy website,[84] using AskSARA, a website tool providing free online, guided self-assessment, links to product suggestions, sources of help and advice and case studies.

In recent years a growing number of projects have involved collaboration between charities and the private sector. Examples in the UK include work by Microsoft with other partners to develop the WeWALK app[85] and smart cane for navigation. Vodaphone also reports on work with the charity Mencap to develop the Connected Living project[86], trialling choice and access to technology through IoT enabled devices and personalised digital services. Another example is the Wayfindr, under development by the RNIB and others, to establish an open standard for Audio Wayfinding and installing Beacon technology in underground train stations.[87] These examples are not intended to be comprehensive but to give some indication of some projects under development in the UK.

Concerning both public and private sectors, blind and partially sighted people report that they still have problems accessing technology. The RNIB points out that from their research:[88]

> Less than one in three people felt they could take advantage of new technology, particularly older people. Overall lots of people said that they don't feel like they're making the most of technology available to them now, but they would be keen to if barriers were removed."

7. Accessibility measures in the built environment

Legal requirements for the built environment have been established and there are some recent initial developments in the design of smart cities that incorporate new technologies.

In England, Wales and Scotland, the Equality Act 2010 states that reasonable adjustment duties apply to the physical features of buildings and the built environment, where these features place a particular disabled person (for employment and let premises) or can be anticipated to place disabled people (for services, post-16 education, private clubs and public functions) at a substantial disadvantage. Similar duties are enacted by the Disability Discrimination Act 1995 and the Disability Discrimination (NI) Order 2006) in Northern Ireland.

[84] Living Made Easy https://www.livingmadeeasy.org.uk/
[85] WeWALK https://wewalk.io/en/
[86] Vodaphone Connected Living Project https://newscentre.vodafone.co.uk/news/mencap-partnership-technology-improves-the-lives-of-people-with-learning-disability/
[87] Zero Project, *Wayfindr,* https://zeroproject.org/practice/uk-royal-london-society-for-blind-people-rlsb/
[88] RNIB *My Voice Research* https://www.rnib.org.uk/rnibconnect/news/my-voice-research

Accessibility standards for new buildings are defined in documents accompanying Building Regulations, mostly in Approved Document M (known as 'Part M')[89] in England and Wales, the Technical Handbooks in Scotland[90] (particularly Section 4.2.7 of the non-domestic handbook) and Technical Booklet R in Northern Ireland[91]. British Standard 8300, revised in 2018, provides a detailed code of practice.

Accessibility and the built environment was reviewed by the House of Commons' Women and Equalities Committee in 2017.[92] They pointed out a number of concerns and made significant recommendations for change: notably that government needs to take greater responsibility for accessibility, greater ambition is needed in setting standards and that 'shared space' street design should end.

There is some limited acknowledgement of the potential for smart cities to enhance accessibility. Tech UK[93] notes the Mayor of London's recognition of the Global Disability Hub[94] as a contributor to developments, for example. The UK government points out that although there is not as yet a national level initiative, a number of city level initiatives exist,[95] with some recognition of accessibility in developments in London, Bristol[96], Manchester and Edinburgh. One example in London is the re-design of ticketing for public transport systems so that passengers may use of all forms of public transport using a single smart card, making payment easier across the board and removing the need for ticketing machines. This system has yet to be introduced in other cities.

7. Skill Development and Work Opportunities

A number of bodies oversee the professional development of engineers in the UK but recruitment of and eliciting the views of disabled people is sporadic rather than systematic. Activity in this area is limited.

The Engineering Council is the regulatory authority for engineering professions in the UK. Professions represented include engineering technicians, ICT technicians,

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[89] UK Government *Access to and use of buildings: Approved Document M* https://www.gov.uk/government/publications/access-to-and-use-of-buildings-approved-document-m

[90] Scottish Government *Technical Handbooks* https://www.gov.scot/policies/building-standards/monitoring-improving-building-regulations/

[91] NI Government, Department of Finance, *Technical Booklet R* http://www.buildingcontrol-ni.com/assets/pdf/TechnicalBookletR2012.pdf

[92] House of Commons (2017) Women and Equalities Committee *Building for Equality: Disability and the Built Environment* https://publications.parliament.uk/pa/cm201617/cmselect/cmwomeq/631/631.pdf

[93] Tech UK *London Open for Smart City Investment* https://www.techuk.org/insights/news/item/10919-london-open-for-smart-city-investment

[94] Global Disability Hub: https://www.ucl.ac.uk/ucl-east/academic-vision/global-disability-innovation-hub

[95] See UK Goverment https://innovateuk.blog.gov.uk/2019/10/08/smart-cities-how-do-the-uk-and-south-korea-compare/ ; https://www.gov.uk/government/speeches/the-uks-leadership-in-smart-cities

[96] Bristol City Council https://www.connectingbristol.org/wp-content/uploads/2019/11/Connecting_Bristol_300819_WEB.pdf

incorporated engineers and chartered engineers. The Council publishes the UK Standard for Professional Engineering Competence (UK-SPEC)[97] and a code of conduct. The UK-SPEC Accreditation of Higher Education Programmes requires students to understand 'customer and user needs' and 'relevant legal requirements'.

The Institute of Engineering Designers (IED)[98] represents professionals working in product design, architecture, mechanical and IT engineering. It promotes continuing professional training and codes of conduct.

For the built environment, the Architects Registration Board (ARB)[99] prescribes Professional Criteria for qualifications, which include an understanding of 'accessibility and inclusion legislation' (3.10). The Royal Institute of British Architects (RIBA) publishes a good practice guide on Designing for Accessibility[100], an Access Audit Handbook and a Construction and Design Manual on Access and Wayfinding,[101] among others.

The Chartered Institution of Civil Engineering Surveyors (CICES)[102] is a qualifying body that regulates, educates and trains civil engineering surveyors. Accreditation requires demonstration of professional competences, including legal knowledge (although accessibility is not identified specifically). The Institution of Civil Engineers (ICE) and the Institution of Structural Engineers (IStructE) maintain core training/development objectives that must be attained before progression to Professional Review (these are also written in general terms). ICE has included a few events about disability in recent years but they have been stand – alone events.

The British Standards Institute (BSI) publishes a guide to managing inclusive design (BS 7000-6:2005, part 6)[103] and well as other more specific standards.

The Cambridge University Inclusive Design group has developed a toolkit[104] that aims to support inclusive design and an orientation to user needs.

Up to £24 million funding from government, universities and industry is to be made available for encouraging new and diverse workers into digital and technology roles. 2,500 university places and 1,000 scholarships are to be offered to students from underrepresented backgrounds through 18 universities working with partner

[97] UK Standard for Professional Engineering Competence (UK-SPEC) https://www.engc.org.uk/UKSPEC
[98] Institute of Engineering Designers https://www.institution-engineering-designers.org.uk/
[99] Architects Registration Board https://arb.org.uk/about-arb/
[100] RIBA (2012) Designing for Accessibility https://www.architecture.com/riba-books/books/public-buildings/product/designing-for-accessibility.html
[101] RIBA https://www.architecture.com/riba-books/books/public-buildings/product/accessibility-and-wayfinding.html
[102] CICES https://www.cices.org/
[103] BS 1SO Managing inclusive design: Guide (BS 7000-6:2005) https://shop.bsigroup.com/ProductDetail/?pid=000000000030142267
[104] Cambridge University Inclusive Design Group http://www.inclusivedesigntoolkit.com/

providers to deliver courses in 28 universities and colleges across England.[105] Disabled people are mentioned as one of the under-represented groups; however, it remains to be seen if this initiative will be successful in reversing the very limited representation of disabled people in this sector of employment and in engineering. Despite other efforts to encourage under-represented groups to apply for training in jobs in engineering, disabled people remain very under-represented in the sector.[106]

Disabled people are involved to a limited extent in product design, although this is often ad hoc. Involvement in design often takes part later on in the process of product development and it is still very rare for disabled people in the UK to have a major role as part of product design teams from the outset.

Training for assessors in social care also does not typically involve learning about products that might assist disabled people in everyday living. The All Party Parliamentary Group for Assistive Technology (APPGAT) and Policy Connect recommend that social service organisations should:

> ..support staff to work with technology by creating specialist dedicated roles within their organisations and empowering staff to develop the mix of technical and clinical skills required to deliver high quality technology enabled care services.[107]

Noting that many smart devices are not yet reliable enough to be consistently used in supporting independent living, APPGAT recommends improved education for health and social care professionals.

As yet there is little indication of any planning for this. The British Association of Social Workers (BASW) has developed training for social workers, as has the Social Care Institute for Excellence (SCIE)[108] but this education is aimed at enabling social workers to do their own jobs more effectively rather than to extend information about technology to service users. Questions are being raised however, about the ethics of how AI has been deployed by local authorities in the course of carrying out social care, for purposes of surveillance and prediction, often without the informed consent of those affected.[109]

University College London (UCL) has developed a master's degree in Disability, Design and Innovation[110], in collaboration with Loughborough University and the

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[105] Office for Students, *Your future in AI and data science* https://www.officeforstudents.org.uk/for-students/study-artificial-intelligence-and-data-science-as-a-postgraduate/
[106] Engineering UK
[107] AAPGAT https://www.policyconnect.org.uk/appgat/sites/site_appgat/files/report/468/fieldreportdownload/appgatsmarthomesbriefing.pdf
[108] BASW Digital capabilities for social workers https://www.basw.co.uk/resources/publications-policies-and-reports/digital-capabilities-social-workers
[109] Community Care https://www.communitycare.co.uk/2019/11/15/using-algorithms-childrens-social-care-experts-call-better-understanding-risks-benefits/
[110] UCL Disability, Design and Innovation MSc https://www.ucl.ac.uk/prospective-students/graduate/taught-degrees/disability-design-innovation-msc

London College of Fashion. The course aims to bridge engineering and policy in the context of disability. This type of interdisciplinary course is as yet quite new in the UK.

While there is still little overlap in professional education and training, a number of training providers, mainly in the charity or third sector aim to bridge the accessibility gap. Abilitynet[111] registered in England and Wales and in Scotland, is an important organisation offering help and support to disabled people to use technology at home, work or education. It also offers accessibility training to a wide range of companies, public authorities and workplaces.

9. Cybersecurity and Safeguards against hate crime and abuse

Under the Equality Act 2010, disabled people should be treated equally to non-disabled people. Protection from discrimination applies in many situations, such as buying or renting property, education, employment, exercise of public functions, goods, services, facilities and transport. The Act cannot be used against an individual person, such as a neighbour for example, but it does cover harassment of a disabled person at a place where they work. Civil court action may also be taken under the Protection from Harassment Act 1997.[112]

In the UK the term 'hate crime' is used to describe “a range of criminal behaviour where the perpetrator is motivated by hostility or demonstrates hostility towards the victim's disability, race, religion, sexual orientation or transgender identity.”[113] It also applies to behaviour motivated by the *perceived* characteristics of the victim, whether or not they do have that characteristic. Because the perpetrator of a hate crime seeks to send a wider message to the community of people of which the victim is part, it is viewed as being more serious compared with other similar crime that does not have this intention. Due to this, in England and Wales sections 28-32 of the Crime and Disorder Act 1998 and in particular sections 145 and 146 of the Criminal Justice Act 2003[114], allow prosecutors to apply for an uplift, or increase, in the sentence for those convicted of a hate crime.

It is well established that hate crime against disabled people is widespread but very under-reported. Within the narrow band that is reported, recent data on hate crime against disabled people shows a clear increase (9% to 8,469) in the number of incidents reported to police[115] although prosecutions remain low, falling from 579

[111] Abilitynet https://www.abilitynet.org.uk/
[112] Protection from Harrassment Act 1997 https://www.legislation.gov.uk/ukpga/1997/40/contents
[113] Crown Prosecution Service *Hate Crime* https://www.cps.gov.uk/crime-info/hate-crime
[114] Criminal Justice Act 2003 https://www.legislation.gov.uk/ukpga/2003/44/section/146
[115] Home Office, *Hate Crime England and Wales 2019/20* https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/925968/hate-crime-1920-hosb2920.pdf

prosecutions in 2018-19 to just 360 in 2019-20.[116] Further, the statistics from the Home Office do not include online hate crime, which, as noted by the Alan Turing Institute, is a serious problem.

Because new technologies present opportunities for abuse, it is important that safeguards are built in. The Alan Turing Institute[117] has called for the following to be part of a new agenda of work in this area, including the responsible use of data – intensive technologies:

1. More research is needed into the long-term effects of online hate
2. Research into online hate should be solution-driven and informed by the concerns and priorities of stakeholders
3. Research into online hate needs to be flexible and responsive, balancing long-term studies with insights that have an immediate impact
4. Definitions in the area of online hate research should be stated clearly, and all assumptions made explicit
5. Data-intensive technologies, if used, must be used responsibly
6. A positive vision of the Internet must be articulated and defended.

A number of developments are underway that are intended to address online harms. It is recognised that organisational self – regulation has not been effective in dealing with harms to users, with content often undermining democratic ideals and algorithms promoting one-sided content to users.

The UK government has consulted on and published a White Paper[118], which sets out measures to regulate the online activities of companies. These include establishing the UK Council for Internet Safety (UKCIS) as a collaborative forum for government, the tech community and civil society. While a key focus is on harms to children, the Council also covers hate crime, extremism and violence against women and girls.

The government also intends to establish an independent regulator for online content and to hold companies accountable. Companies will have a statutory duty of care towards users of their platforms and responsibility for harm done. Monitoring will however, be largely limited to harm against children and terrorist activities.

These actions have been broadly welcomed but many are as yet untested. It remains to be seen as to whether they will apply to and regulate personal equipment used by disabled people. Although the work on online harms is very important for

[116] Disability New Service https://www.disabilitynewsservice.com/disability-hate-crime-prosecutions-plummet-while-home-office-stays-silent/
[117] Alan Turing Institute https://www.turing.ac.uk/news/new-policy-briefing-calls-more-research-long-term-effects-online-hate
[118] UK Government *Online Harms White Paper* https://www.gov.uk/government/consultations/online-harms-white-paper/online-harms-white-paper#conclusion-and-next-steps

cyberbullying, interference in personal equipment has the potential to be extremely threatening and it may well need more stringent safeguards.

10. Examples of good practice in inclusion of disabled people in developing policy on new technologies

As noted above, despite progress, there is still much more to be done in the UK to meaningfully involve disabled people in the development of relevant technology.

New technologies have the potential to make a real difference to everyday living for disabled people. The more that technological solutions are integrated into mainstream technology, used by the general population, the more likely they are to be successful. Use of specialised technology alongside more generally used technology can cause incompatibility problems [119] and the House of Commons has noted that although specialist equipment may be a good option, mainstream competitors increasingly provide the same functions at lower cost, with greater flexibility and compatibility with existing systems.

AbilityNet holds an annual awards ceremony, the Tech 4 Good awards.[120] New developments in disability – related technology are recognised, although the awards have a wider remit. Private sector companies sponsor a number of award categories and contributors to the field are recognised.

Organisations of disabled people in the UK have put effort into user involvement, making it easier to locate potential collaborators. 'Shaping our Lives'[121] was formed with the intention of improving user involvement in a wide range of activities. So far, most effort has been directed towards involvement in service development and provision, with a focus or redressing power imbalances between service providers and service users. However the network has potential as a broader consultation network too.

The Alan Turing Institute has a work strand on AI and Inclusion that is concerned with the use of AI for and by disabled people.[122] A number of projects are underway although they note that as yet there is no roadmap for this and ethics and an overview of unmet need in relation to assistive products are missing. The organisation lists several innovative AI projects and reports on the intersection of technology and the protected characteristics of the Equality Act 2010. They have

[119] House of Commons Work and Pensions Committee, Assistive Technology, Tenth Report of Session 2017–19 https://publications.parliament.uk/pa/cm201719/cmselect/cmworpen/673/673.pdf
[120] Tech 4 Good awards https://www.tech4goodawards.com/finalists-2020/
[121] Shaping Our Lives https://www.shapingourlives.org.uk/
[122] Alan Turing Institute *AI and Inclusion* https://www.turing.ac.uk/research/research-projects/ai-and-inclusion

also carried out research into potential and actual barriers and set out priorities for future development.

Other new initiatives underway include the AT 2030[123], concerned with making accessible technology available at an international level. Working with the Global Disability Innovation Hub, the initiative developed as part of the legacy of the London 2012 Olympic Games. The GDI hub is working with others to develop an agenda for AI research.[124]

10. Conclusions

People with deafblindness and disabled people have broadly welcomed the opportunities presented by new technologies. However, most still do not have much information about its potential or access to it in the UK.

Disabled people are largely absent from design teams, may face complex and bureaucratic systems for gaining access to assistive devices and have little input into policy on new technologies. At the same time, improved ethical governance of technology is high on the policy agenda and this may allow an opportunity for greater recognitions of the problems and opportunities for disabled people.

An established body of law and policy addresses discrimination and exclusion in the UK, even if disadvantage is still widespread. Institutions are now mostly but not wholly discredited as a form of care provision, at least for younger disabled people. It is therefore important that the ways that technology is used should support the upholding of disabled people's human rights, especially the right to independent living in the community and access to the whole range of life experiences. Because disability awareness / equality training is largely absent in education for engineers, there is a risk that new technology could erect new barriers for disabled people.

People with deafblindness and disabled people are disproportionately likely to be unemployed and living on a low income and for this reason, access to equipment via public funds is important. The UK systems for receiving support, including technology, are often complex. Eligibility rules vary with the size of the local authority budgets and there are often refusals and legal appeals. Although larger sums are available for household adaptations, expenditure on small items of equipment for personal use are more likely to be approved compared with larger items. It is notable that some more expensive items, notably robots, have been deployed in institutions and ownership is with carers rather than disabled people themselves.

[123] AT 2030 https://at2030.org/powering-inclusion:-ai-and-assistive-technology.-call-for-evidence./
[124] AT 2030 *Call for Evidence* https://at2030.org/powering-inclusion:-ai-and-assistive-technology.-call-for-evidence./

Accessibility laws apply in the UK, including recent directives from the EU. However, the UK's exit from the EU means that the EU Accessibility Act will not automatically apply, due to the long transposition period and a deadline after Brexit transition period ends on the 31 December 2020.

The UK government has put a strong emphasis on the importance of investing in new technologies and their application to many areas of life. Plans for regulation and improved standards are underway but largely lag behind innovations.

Use of cameras is a contested issue in the UK and their deployment as compensation for sight and recognition is not recognised. Restrictions on their use outside the house limit the potential of innovative technology such as the SUITCEYES HIPI to be used to its full potential by people with deafblindness for face and object recognition. Similarly, the data processing that is involved must be authorised, with appropriate and robust privacy safeguards for all involved.

The development of smart cities in the UK provides an opportunity to embed enabling technology in the environment, and this may be particularly useful for improving accessibility and reducing the amount of hardware that must be carried in wearables. As yet, such developments are scarce, although a few pilot projects aim to improve wayfinding in specific locations, such as along transport systems. New projects under development may offer further options for improving environmental accessibility. In doing this, it is essential that robust safeguards against harassment, abuse and hate crime are put in place.

11. Recommendations

Participation

All parts of the UK should fully recognise accessibility and language rights in respect to the participation of people with deafblindness.

Disabled people need affordable access to technology. This includes both access to information about technology and reasonably priced means of obtaining it.

Adequate resources for upgrading, maintenance and repair of devices should be built in to design and into packages of care.

Disabled people should not be made to choose between either human or technological support.

Effective Product Development and Use

Purposeful strategies are needed to ensure well-matched and effective devices. As experts by experience, disabled people must have early opportunities to be involved with the design of AI technology intended to meet their needs. This must include

education and training for disabled people to design, take part and evaluate initiatives effectively.

Professionals, including designers, disabled people's organisations and social care professionals need to be well informed about subjects very different from their own areas of expertise. As well as training and education for students in the different fields, there should be many opportunities for interdisciplinary continuing professional development and a variety other ways to exchange ideas and insights.

Disabled people should be effectively involved in initiating, developing and monitoring developments.

Law and Policy on New Technologies

The ethical application of new technologies should be effectively regulated by an independent organisation. This is necessary for society as a whole and must include the elimination of bias, omission of and discrimination against disabled people. Oversight should be continual and not simply delegated to AI itself.

Improved privacy safeguards are needed, especially for potentially intrusive technologies essential for daily living. Access to technology must not require disabled people to consent to personal intrusion and use of their data by others. Personal data generated by use of technology should be under the control of the end users and those directly impacted.

Accessibility, with adequate safeguards, should be built in to smart city developments at early stages, rather than added as an afterthought.

Safeguards against the use of new technology for the purpose of hate crime must be built in from the start and further resources dedicated to tackling it when it occurs.