

**The Human
Rights, Big Data
and Technology
Project**



A Digital Cage is Still a Cage*

**How can new and emerging digital
technologies advance, rather than put at risk,
the human rights of older people who draw on
social care?**

Neil Crowther & Lorna McGregor

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* Title

The title to this report, 'A Digital Cage is Still a Cage' is inspired by the oft-cited statement by Lady Hale that a 'gilded cage is still a cage' in the UK Supreme Court case of *P v. Cheshire West and Chester Council and Another* [2014] UKSC 19 (19 March 2014), at paragraph 46.

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EXECUTIVE SUMMARY

In the field of social care, a range of new and emerging technologies are drawn upon by older people, their families, and state and independent care providers for different purposes, including to:

- monitor health and wellbeing, for example, by detecting a fall;
- provide companionship or to increase connectivity with friends and relatives;
- carry out discrete household tasks, such as vacuuming;
- stimulate long-term memory and set reminders for particular tasks, such as to take medicine;
- support decision-making by care providers;
- detect pain;
- monitor staff performance.
- provide a 'digital marketplace' to find, buy and sell social care.

Some of these technologies, such as smart assistants, are not designed or developed for the delivery of social care specifically or targeted at older people as a user group. However, they are used by older people, their families, or care providers as a tool in social care. Other technologies are aimed at older people, as reflected by a rapidly developing market for 'age tech'. Age tech encompasses technology with specific functions, such as to monitor for falls, and can integrate a range of technologies within customised smart homes, for example, smart homes designed specifically for people with dementia.

In many states, people largely draw on formal social care from private, voluntary and community sector provider organisations. This care may be commissioned by national or local government. However, in contexts in which publicly funded social care is limited, many individuals and families offer or arrange such care themselves, a challenge accentuated where families live far apart. Some care providers draw on digital technologies to maintain records and plan and monitor care delivery. They may also experiment with new and emerging technologies, often as alternatives to human care-workers, such as technologies that are marketed as able to monitor the movement of residents in care homes or detect seizures as well as to assist in human caregiving, such as facial recognition technologies to help detect pain in people who are non-verbal, for example due to dementia or a stroke. Outside of or alongside formal care, older people and their families are also turning to new and emerging technologies not only as a means of communication but also as a safeguard, for example, to alert their family to a fall.



How New and Emerging Technologies can Advance or Deny Older People's Human Rights

New and emerging technologies already play a role in, or have great potential to feed into, and support the realisation of, a rights-based model of social care. Such a model is not about simply 'maintaining' a person or the transactional provision of food or medication. Rather, at its core are the underlying principles of human rights, namely human dignity, fairness, equality, inclusion, participation, and empowerment. A rights-based model of care underscores the agency of older people to make decisions about their care and to claim their human rights to choice and control over their lives. This not only requires a rights-based approach to health and care but also the fulfilment of the right to independent living, the foundations of which are autonomy and independence in decision-making, with support where appropriate; liberty and security of the person; and inclusion and participation in the life of the wider community on an equal basis with others. When used as part of a rights-based model of care, new and emerging technologies may give older people greater choice and control over daily life and the support they draw upon, rather than having decisions taken away from them, including by supporting people with cognitive impairments with memory, communication, and decision-making. These technologies may empower older people to live more autonomous lives, for example by postponing or avoiding altogether moving into residential and nursing care homes. They could help ensure that people are safe, without safety coming at a disproportionate cost to their liberty or privacy. New and emerging technologies may help to connect people with their families and local community. By delivering some of the more 'life and limb' dimensions of care, they could help reshape human 'care-giving' to focus on supporting people to achieve or maintain meaning, purpose, and relationships. Technology may also beneficially assist in the monitoring and regulation of services, both at the level of identifying good or poor practice, as well as, for example, harnessing data analytics to identify risks and to ensure the more equitable distribution and targeting of resources.

At the same time, new and emerging technologies could be used – intentionally or unintentionally – to adversely impact older people's human rights and contribute to their segregation and isolation from wider community. The current design and use of many technologies pose acute risks to the right to privacy, which is particularly serious given that these technologies are deployed in people's homes, including in bedrooms and bathrooms, and may be recording, processing and sharing data about the most intimate details of older people's lives. These risks may increase as technologies become more sophisticated, and are able to interact, for example, within the context of a smart home.



At their most extreme, the use of new and emerging technologies could replicate the worst features of institutional care rather than facilitate independent living and inclusion within the community. People could find themselves subject to regimes of daily living either pre-programmed, or evolved through machine learning, that limit choice and involve coercion. This could include new and emerging technologies being programmed to lock doors should a person attempt to leave their home on their own or at an unscheduled time, potentially subjecting them to restrictions to their freedom of movement, and even de facto forms of deprivation of liberty, through techno-restrictions. Where humans are still involved in the delivery of care, they may be subject to management and monitoring by these technologies, deepening 'time and task' models of care delivery and denying them the opportunity to practice empathetic, relational care, and support. Some forms of new and emerging technologies may replicate modes of 'substitute decision-making' that have historically denied people with cognitive impairments their legal personhood and autonomy. They may be introduced without meaningful consent or the input of older people, resulting in technology being 'done' to them rather than at their direction. When framed as a solution to deal with diminishing resources, there is also the risk that they accentuate existing challenges in social care, and potentially entrench isolation and feelings of loneliness where people live in, but become completely isolated from, the wider human community, interacting mainly with technologies.

Between these two extremes lie the same risks emphasised by Lady Hale in the UK Supreme Court case of *Cheshire West*.¹ She observed that if a person living in the community is denied the possibility of leaving their home without permission and is subject to close supervision, then, '[t]he fact that my living arrangements are comfortable, and indeed make my life as enjoyable as it could possibly be, should make no difference. A gilded cage is still a cage.'. Similarly, the use of new and emerging technologies in the lives of older people living in the community could offer the veneer of autonomy, liberty and inclusion, yet their human rights may still be compromised: a digital cage is still a cage.

All of these futures are possible, and indeed may co-exist; how these risks and opportunities manifest themselves depends on a range of factors. While not exhaustive, these factors include who decides whether particular technologies are used and for what purpose; the design and function of the technology; who decides

¹ *P v. Cheshire West and Chester Council and Another* [2014] UKSC 19 (19 March 2014).



upon who accesses and uses the data and for what purpose, raising the question of whether older people can meaningfully consent and control whether and how their data is collected, stored, deleted, shared, or sold and the data analytics applied to it; whether the technology replaces or complements services or decisions typically made by humans; and the safeguards in place to protect a person's dignity, autonomy, and human rights.

Our report sets out the current challenges and debates surrounding social care in general and maps the current technologies being used by local governments, independent care providers, individuals, and families to support social care. We show how, depending on their design and deployment, and the framework in place to protect human rights, new and emerging technologies can pose significant risks to older people's enjoyment of human rights or enhance their autonomy and dignity, supporting them to live independently and participate in the community, moving away from models of care based on residential and nursing homes.

Putting a Human Rights-Based Approach to the Use of New and Emerging Technologies on the Social Care Agenda

With some exceptions, there is relatively little literature on the ethical and human rights implications of the use of new and emerging technologies in the context of social care. Ethical and human rights considerations appear to play little part in the commissioning, design, or application of such technologies in social care. Yet, how new and emerging technologies are designed, regulated, and governed in the care sector has serious implications for whether they enhance or deny older people's human rights.

Our report concludes that significant work is needed to first understand, particularly from the perspective of older people as a diverse group, whether and how new and emerging technologies can improve later life, including in the context of social care. The development and deployment of individual technological applications and the wider regulation of the tech sector in a manner that is ethical and respects human rights will be critical to the protection of older people's human rights. However, the future direction of technology in this field will also depend on how social care is conceived. We find that the chances of new and emerging technologies contributing to the advancement and enjoyment of rights will be greatly enhanced if they are introduced into social care environments that assume a rights-based approach to care. We therefore suggest that securing a rights-based approach to care should be prioritised as part of a wider commitment to



grounding the design, development, and deployment of new and emerging technologies in social care in human rights.

Accordingly, in this report we suggest that the role of technologies in older people's lives is inextricably linked to the wider vision, strategies, and policies for social care. If we choose a future in which care amounts to little more than maintenance, then it is more likely that technology will be designed and employed to help maintain people alive, but not living a life. If we choose a future in which people are supported to live a life they have reason to value and in which they are included and able to fully participate in the wider community, then technology will be developed to support that goal.

Of equal importance, especially given the widespread consumption and deployment of digital technologies by private citizens to the ends of social care, is the adoption of a human rights-based approach to the design, development, and deployment of new and emerging technologies by states and private actors, including technology companies and care providers, taking into account the diverse and intersectional experiences, goals, and needs of older people. This includes reassessing existing data protection frameworks to ensure that they adequately protect older people from situations in which their access to low-cost or free internet or AI-enabled devices is conditioned on restrictive terms and conditions that allow their data to be collected, stored, analysed, and sold in ways that adversely affect their privacy and wider human rights, and contributes to structural inequalities. Moreover, where states and private care providers provide AI-enabled devices, the purposes for which they collect, store, analyse, share and sell data may need to be subject to specific regulation.

Within both frameworks, much more attention is needed to understand the extent and nature of current use of new and emerging technologies within social care and the experience of older people, their families, and caregivers of these technologies. This knowledge base and the meaningful participation of older people is critical in the shaping of normative and operational principles on the use of new and emerging technologies within a rights-based approach to social care and to prevent intersectional discrimination in the design and development of AI-enabled technologies and services and decision-making processes using such technologies. This would mean avoiding technology being 'done to' people and instead assessing the ways in which it can enable older people to people enjoy their rights to live independently, make autonomous decisions and



participate in community life as set out in the UN CRPD and to enhance the quality of later life without having to trade-off or give up other rights.²

Our report also recommends that:

1. Overcoming Digital Divides

If older people are to have the option of using new and emerging technologies as tools to advance their human rights, core baseline issues, such as overcoming the intersectional digital divides facing older people requires urgent attention, including to avoid the realisation of two digital futures, whereby some are able to enjoy the benefits of technology whereas others are excluded or subjected to technology being ‘done to them’.³ Digital divides continue to exist at multiple levels, such as ongoing barriers to the affordability and accessibility of the internet and new and emerging technologies more broadly, including for older people with visual, aural and cognitive impairments. Strengthening data and technology literacy is also a critical pre-condition to the exercise of meaningful consent to the use of new and emerging technologies in older people’s lives, as well as being able to fully utilise the different functionalities offered by particular technologies.

Developing effective strategies to overcome the digital divides experienced by older people and the inaccessibility of certain technologies requires prioritisation as an overall policy objective for states and technology designers and developers. However, it is important that it is not only treated as a contained policy objective on overcoming digital divides but also integrated within wider social care law and policy. For example, overcoming digital divides and the inaccessibility is inextricably linked to initiatives to increase connectivity as part of public health policies.

² Council of the European Union, ‘Conclusions on Human Rights, Participation and Well-Being of Older Persons in the Era of Digitalisation’ (9 October 2020), at §27,

<https://www.consilium.europa.eu/en/press/press-releases/2020/10/12/improving-the-well-being-of-older-persons-in-the-era-of-digitalisation-council-adopts-conclusions/>

³WHO, Decade of Healthy Ageing: Baseline Report (2020), 67, 126.



2. Identifying Red Lines in the Design, Development or Deployment of New and Emerging Technologies for Social Care

Within the wider tech and human rights field, over 15 US cities have introduced bans on the use of facial recognition technologies by law enforcement⁴ and civil society organisations have instituted wider campaigns to ‘Ban the Scan’⁵ and ‘Reclaim your Face’.⁶ The draft EU AI Act also prohibits the use of AI-enabled technologies categorised as ‘unacceptable’. To date, debates and policy initiatives on possible ‘AI red-lines’ have not closely examined whether certain types of technology or use cases in the field of social care should be prohibited. However, given that new and emerging technologies are likely to be used in older people’s homes and for their care and support, this report highlights the critical importance of further analysis of whether AI red-lines should be applied to the use of new and emerging technologies in social care and support.

Clear examples emerging from this report include where new and emerging technologies are used within the community to deprive older people of their liberty or to replicate the control and coercion associated with institutions, even if implemented within their own homes. Article 5(a) of the draft EU AI Act is of relevance to the field of social care in prohibiting, ‘the placing on the market, putting into service or use of an AI system that deploys subliminal techniques beyond a person’s consciousness in order to materially distort a person’s behaviour in a manner that causes or is likely to cause that person or another person physical or psychological harm’. Article 5(b) also prohibits ‘the placing on the market, putting into service or use of an AI system that exploits any of the vulnerabilities of a specific group of persons due to their age, physical or mental disability, in order to materially distort the behaviour of a person pertaining to that group in a manner that causes or is likely to cause that person or another person physical or psychological harm’. Much greater analysis and discussion is required into the implications of these draft prohibitions and whether they are sufficient or require extension in the field of social care, particularly with regard to instances in which the use of new and

4 Nathan Sheard and Adam Schwartz, ‘The Movement to Ban Government Use of Face Recognition’ *Electronic Frontier Foundation* (5 May 2022).

5 Amnesty International, Ban the Scan Campaign, <https://www.amnesty.org/en/petition/ban-the-scan-petition/>

6 EDRI, Reclaim Your Face Campaign, <https://reclaimyourface.eu>.



emerging technologies inhibits choice and control, restricts cognitive autonomy or results in a new form of substitute decision-making.⁷

For other technologies, such as so-called ‘companion’ robots, their use or provision by states or private care organisations may not be subject to an outright ban, but may be conditional on their integration with wider strategies and policies aimed at preventing isolation and segregation and increasing connectivity and inclusion within the community, and never as a replacement to fostering human connection.

3. The Establishment of Clear Safeguards

Beyond AI red-lines, the development of clear safeguards is needed in both the decision-making process to introduce new and emerging technologies into social care as well as the establishment of effective oversight and monitoring systems and complaint processes. As we have recommended in previous research by the Human Rights, Big Data and Technology Project, such an approach should be informed by international human rights standards and norms and ensure the meaningful participation of older people.

(a) Meaningful consent

Where technologies are used in older peoples’ lives, this report underscores that it must be with their meaningful consent and not at the direction of others, even if with a benevolent purpose, such as to increase security or safety. Meaningful consent cannot be given if the person does not have detailed but accessible information on the benefits and functionalities of the technology as well as the full risks. If in the context of formal care, technology cannot be presented by state or private caregivers as an ‘either/or’ situation, meaning that older people must also be provided with a non-technological alternative. They must also always have the opportunity to change their mind and decide they no longer want the technology within their lives, without any adverse consequences to their care and support.

Where individuals are deemed to ‘lack’ legal capacity, they must be supported in their decision-making about the role of technologies in their lives rather than having their decision-making capacity removed from them

⁷ European Commission, ‘Proposal for a Regulation of the European Parliament and of the Council Laying Down Harmonised Rules on Artificial Intelligence (Artificial Intelligence Act) and Amending Certain Union Legislative Acts, COM/2021/206 final (21 April 2021).

through substituted decision-making. Moreover, it is possible that some individuals consent to the role of new and emerging technologies in their lives within advanced care directives. In this regard, much more work is needed to examine the specificity that would be required within such directives, particularly as the nature and intrusiveness of specific technologies vary depending on factors such as the model used, the actor implementing it, and the governance and regulatory framework. Moreover, technologies are constantly evolving.

(b) Transparency and Safeguards by Companies Designing, Developing and Selling ‘Ageing Tech’

This report highlights that new and emerging technologies may be purposefully developed for older people, often referred to as ‘age tech’, or used as part of care and support, even if not marketed for that specific purpose. In both cases, this report cites research finding that older people feel excluded from the conceptualisation and design of these technologies with the result that they may not be fully and effectively designed and developed to enable them to live high-quality lives. In this regard, a key recommendation of this report is for both ‘age tech’ and technology companies more broadly to involve diverse groups of older people in the conceptualisation and design of new and emerging technologies to ensure that they are developed to maximise their goals, needs and interests and adverse human rights impacts are identified and addressed at an early stage.

The report also highlights the need to create opportunities to test new and emerging technologies and the provision of detailed but clear and usable information on how to use the technology to its full extent and protect human rights, in easy to read and accessible formats in order to enhance the prospects of such technologies advancing, and not harming, human rights. Help desks staffed by humans would also facilitate the accessibility and useability of such technologies.

(c) Transparency and Safeguards by Private and State Care Providers

At the stage at which local government or private care providers are considering offering new and emerging technologies, the reasons for such a proposal should be publicly documented, making clear whether the proposals are to meet objectives such as cost-reductions, and whether they are aimed at replacing an existing service or as additions to the care and support already offered. An impact assessment should also be carried out to assess the potential impact the technology could have on the safety, security, and human rights of older



people and other people who come into contact with that person, such as family members, friends and care workers or informal carers. The design of impact assessments should involve older people and their advocates to ensure the tailoring of the assessment to the human rights of older people.

The impact assessment should not refer to the type of technology generically, such as acoustic listening, but the actual product or model being considered. It should include a comparison with the features of other technologies capable of carrying out a certain function, such as monitoring for falls, in order to see the range of technological options available and their advantages and disadvantages. It should also include assessments of whether specific features, such as collection of data, or the use of cameras or facial recognition, are the only way in which to meet a particular goal and whether they are necessary for the technology to function or an additional feature for commercial benefit or to feed into other goals of the state.

Where the technology will be offered by a private company, as is often the case, the human rights of older people should feature centrally in the procurement process and a risk assessment into that company carried out from this perspective. Consideration should be given to whether any data gathered should be accessible, shared, and usable by the care provider, any other state actors or third-party actors, or the company providing the technology. Such assessments should not simply be between the care provider and the technology provider but should involve meaningful stakeholder consultation, particularly with those who are to use the technology, or have it used in their lives.⁸ As noted above, the use of the technology in an individual's life will require separate meaningful consent and include the right to refuse the use of technology in their lives or to require its removal, without consequence or to the detriment of their care.

Local government and independent care providers should also have ongoing monitoring and oversight practices in place, including for independent regulatory bodies, such as national human rights commissions, care commissions, national preventive mechanisms and independent monitoring mechanisms under the Convention on the Rights of Persons with Disabilities to ensure that the use of technologies complies with human rights, alongside effective and accessible complaints mechanisms.

⁸ UNHRC, 'UN Guiding Principles on Business and Human Rights' (2011) UN Doc A/HRC/17/31 (UNGPs), Principle 18, https://www.ohchr.org/documents/publications/guidingprinciplesbusinesshr_en.pdf



The establishment of such safeguards is a minimum requirement to protect older people's human rights. If new and emerging technologies are to play a role in enhancing or securing the enjoyment of human rights, much greater attention is needed into the types of processes required to ensure that older people are effectively supported, where necessary, to make autonomous decisions about the use of new and emerging technologies in their lives and to exercise meaningful choice.



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I. INTRODUCTION

In the social care field, a range of new and emerging technologies are drawn upon by older people, their families, and state and independent care providers for different purposes, including to:

- monitor health and wellbeing, for example, by detecting a fall;
- provide companionship or to increase connectivity with friends and relatives;
- carry out discrete household tasks, such as vacuuming;
- stimulate long-term memory and set reminders for particular tasks, such as to take medicine;
- support decision-making by care providers;
- detect pain;
- monitor staff performance.
- provide a 'digital marketplace' to find, buy and sell social care.

Some of these technologies, such as smart assistants, are not designed or developed for the delivery of social care specifically or targeted at older persons as a user group. However, they are used by older people, their families or care providers as a tool in social care. Other technologies are aimed at older people, as reflected by a rapidly developing market for 'age tech'. Age tech encompasses technology with specific functions, such as to monitor for falls, and can integrate a range of technologies within customised smart home, for example, smart homes designed specifically for people with dementia.¹

In many states, people draw on formal social care from private, voluntary and community sector provider organisations. This care may be commissioned by national or local government. However, in contexts in which publicly funded social care is limited, many individuals and families arrange and fund such care themselves, a challenge accentuated where families live far apart. Some provider organisations draw on digital technologies to maintain records and plan and monitor care delivery. They may also experiment with new and emerging technologies, often as alternatives to human care-workers, such as technologies that are marketed as able to monitor the movement of residents in care homes or detect seizures as well as to assist in human caregiving, such as facial recognition technologies to help detect pain in people who are non-verbal, for example due to

¹ See Parts II.E.1. and 3 and Part III.E. and G.

dementia or a stroke. Outside of or alongside formal care, older people and their families are also turning to new and emerging technologies not only as a means of communication but also as a safeguard, for example, to alert the family to a fall.

New and emerging technologies already play a role in, or have great potential to feed into, and support the realisation of, a rights-based model of care. Such a model is not about simply ‘maintaining’ a person or the transactional provision of food or medication. Rather, at its core are the underlying principles of human rights, namely human dignity, fairness, equality, inclusion, participation, and empowerment. A rights-based model of care underscores the agency of older people to decide upon their care and to claim their human rights to choice and control over their life. This not only requires a rights-based approach to health and care but also the fulfilment of the rights to independent living, the foundations of which are autonomy and independence in decision-making, with support where appropriate;² liberty and security of the person;³ and inclusion and participation in the life of the wider community on an equal basis with others.⁴ When used as part of a rights-based model of care, new and emerging technologies may give older people greater choice and control over daily life and the support they use, rather than having decisions taken away from them, including by supporting people with cognitive impairments with memory, communication, and decision-making. These technologies may allow older people to live more autonomous lives, for example by postponing or avoiding altogether moving into residential and nursing care homes. They could help ensure that people are safe, without safety coming at a disproportionate cost to their liberty. New and emerging technologies may help to connect people with their families, the local community and to peer support. By delivering some of the more ‘life and limb’ dimensions of care, they could help reshape human ‘care-giving’ to focus on supporting people to achieve or maintain meaning, purpose, and relationships. Technology may also beneficially assist in the monitoring and regulation of services, both at the level of identifying good or poor practice, as well as, for example, harnessing data analytics to identify risks and to ensure the more equitable distribution and targeting of resources.

² See, UN Committee on the Rights of Persons with Disabilities, ‘General Comment No. 1- Article 12: Equal Recognition Before the Law’ CRPD/C/GC/1 (19 May 2014).

³ See, UNGA ‘Report of the Committee on the Rights of Persons with Disabilities: Guidelines on the right to liberty and security of persons with disabilities’ 72nd session A/72/55 (2017).

⁴ See, UN Committee on the Rights of Persons with Disabilities, ‘General Comment No. 5 on Living Independently and Being Included in the Community’ CRPD/C/GC/5, (27 October 2017).



At the same time, new and emerging technologies could be used – intentionally or unintentionally – to adversely impact older people’s human rights and contribute to their segregation and isolation from the wider community. The current design and use of many technologies pose acute risks to the right to privacy, which is particularly serious given that these technologies are deployed in people’s homes, including in bedrooms and bathrooms, and may be recording, processing and sharing data about the most intimate details of older people’s lives. These risks may increase as technologies become more sophisticated, and are able to interact, for example, within the context of a smart home.

At their most extreme, the use of new and emerging technologies could replicate the worst features of institutional care rather than facilitate independent living and inclusion within the community. People could find themselves subject to regimes of daily living either pre-programmed, or evolved through machine learning, that limit choice and involve coercion. This could include new and emerging technologies being programmed to lock doors should a person attempt to leave their home on their own or at an unscheduled time, potentially subjecting them to restrictions to their freedom of movement, and even de facto forms of deprivation of liberty, through techno-restrictions. Where humans are still involved in the delivery of care, they may be subject to management and monitoring by these technologies, deepening ‘time and task’ models of care delivery and denying them the opportunity to practice empathetic, relational care and support. Some forms of new and emerging technologies may replicate modes of ‘substitute decision-making’ that have historically denied people with cognitive impairments their legal personhood and autonomy. They may be introduced without meaningful consent or the input of older people, resulting in technology being ‘done’ to them rather than at their direction. When framed as a solution to deal with diminishing resources, there is also the risk that they accentuate existing challenges in social care, and potentially entrench isolation and feelings of loneliness where people live in, but become completely isolated from, the wider human community, interacting mainly with technologies.

Between these two extremes lie the same risks emphasised by Lady Hale in the UK Supreme Court case of *Cheshire West*.⁵ She observed that if a person living in the community is denied the possibility of leaving their home without permission and is subject to close supervision, then, ‘[t]he fact that my living arrangements are

⁵ *P v. Cheshire West and Chester Council and Another* [2014] UKSC 19 (19 March 2014).



comfortable, and indeed make my life as enjoyable as it could possibly be, should make no difference. A gilded cage is still a cage.’ Similarly, the use of new and emerging technologies in the lives of older people living in the community could offer the veneer of autonomy, liberty and inclusion, yet their human rights may still be compromised: a digital cage is still a cage.

How these risks and opportunities manifest themselves depends on a range of factors. While not exhaustive, these factors include who decides whether particular technologies are used and for what purpose; the design and function of the technology; who decides upon who accesses and uses the data and for what purpose, raising the question of whether older people can meaningfully consent and control whether and how their data is collected, stored, deleted, shared, or sold and the data analytics applied to it; whether the technology replaces or complements services or decisions typically made by humans; and the safeguards in place to protect a person’s dignity, autonomy, and human rights.

Overall, two futures seem possible: one in which people are instrumentalised by new and emerging technologies to contain costs and ‘maintain’ older people, and another in which these technologies become instruments for achieving the best conditions for later life, based on rights, autonomy, dignity, and social connection. Existing inequalities already played out in the availability, nature, and design of social care, and digital divides, make it more likely that these two futures will co-exist. Significant work is therefore needed to realise a future in which new and emerging technologies positively contribute to the enjoyment of rights, autonomy, dignity, and inclusion of older people in their communities.

While there is a burgeoning literature and practice on the overall ethics and human rights implications of the design, development and deployment of new and emerging technologies,⁶ and their use by specific actors, such as law enforcement, there is comparatively little on the ethical and human rights implications of the role

⁶ Lorna McGregor, Vivian Ng, Ahmed Shaheed et al, ‘The Universal Declaration Of Human Rights at 70: Putting Human Rights at The Heart Of The Design, Development, And Deployment Of Artificial Intelligence’, *Human Rights Big Data and Technology Project* (2018); Lorna McGregor, Daragh Murray and Vivian Ng, ‘International Human Rights Law as a Framework for Algorithmic Accountability’, 68 *International and Comparative Law Quarterly* 309 (2019); Mathias Risse, ‘Human Rights and Artificial Intelligence: An Urgently Needed Agenda’, 41 *Human Rights Quarterly* 2019, 1-16; Ben Wagner, ‘Ethics as an Escape from Regulation - From “Ethics-Washing” to Ethics-Shopping?’ in Emre Bayamlioglu, Irina Baraliuc, Liisa Janssens and Mireille Hildebrandt (eds), *Being Profiled: Cogitas Ergo Sum: 10 Years of Profiling the European Citizen* (2018); Eileen Donahoe and Megan MacDuffee Metzger, ‘Artificial Intelligence and Human Rights’, 30 *Journal of Democracy* 115 (2019); Brent Daniel Mittelstadt, Patrick Allo, Mariarosaria Taddeo, Sandra Wachter and Luciano Floridi, ‘The Ethics of Algorithms: Mapping the Debate’, *Big Data & Society* 1 (2016).



of new and emerging technologies in the context of social care. Exceptions to this include Scottish Care’s ‘A Human Rights Charter for Technology and Digital in Social Care’⁷ and the report of the UN Independent Expert on the enjoyment of all human rights by older persons on the impact of automation on the rights of older persons.⁸ Ethical and human rights considerations appear to play little part in the commissioning, design, or application of such technologies in this area of life. For example, one interviewee for this report noted how debate about human rights and AI-enabled technologies centred on ‘[d]emocracy, expression of opinion and financial services, but care is not on the agenda’.⁹ Yet, how new and emerging technologies are designed, regulated, and governed in the care sector has serious implications for whether they enhance or deny older people’s human rights.

The development and deployment of individual technological applications and the wider regulation of the tech sector in a manner that is ethical and respects human rights will be critical to the protection of older people’s human rights. However, the future direction of technology in this field will also depend on how social care is conceived. Accordingly, in this report, we suggest that the role of technologies in older people’s lives is inextricably linked to the wider vision, strategies, and policies for social care. If we choose a future in which care amounts to little more than maintenance, then it is more likely that technology will be designed and employed to help ‘maintain’ people alive, but not living a life. If we choose a future in which people are supported to live a life they have reason to value and in which they fully participate and are included in the wider community, then technology will be developed to support that goal.

In Part II of this report, we set out the current challenges and debates surrounding social care in general and map the current technologies being used by local governments, independent care providers, individuals, and

7 Donald Macaskill, ‘TechRights: Human Rights, Technology and Social Care’, Scottish Care (2018), at 27 <https://scottishcare.org/wp-content/uploads/2019/11/TechRights-Human-Rights-Technology-and-Social-Care.pdf>; Scottish Care, ‘A Human Rights Charter for Technology and Digital in Social Care Guidance Document’ (2019), <https://scottishcare.org/wp-content/uploads/2019/11/Guidance-Documents-for-Human-Rights-Charter-for-Technology-Digital-in-Social-Care.pdf>. See also, Health and Social Care Alliance Scotland, *Human Rights Principles in Digital Health and Social Care* (April 2021) [Human-rights-principles-for-digital-health-and-social-care-April-2021.pdf](https://alliance-scotland.org.uk/wp-content/uploads/2021/04/Human-rights-principles-for-digital-health-and-social-care-April-2021.pdf) (alliance-scotland.org.uk)

8 UN Human Rights Council, ‘Report of the Independent Expert on the enjoyment of all human rights by older persons’ A/HRC/36/48 (21 July 2017); UN Human Rights Council, ‘Report of the Special Rapporteur on the rights of persons with disabilities’ A/HRC/49/52 (28 December 2021); Piers Gooding, Simon Katterl, Jonah Bossewitch, Lydia X. Z. Brown, Leah Harris, James Horton, Keris Myrick, Kelechi Ubozoh and Alberto Vasquez, *Digital Futures in Mind: Reflecting on Technological Experiments in Mental Health & Crisis Support* (University of Melbourne, 2022) (forthcoming).

9 Interview 2 (14 October 2019).



families to support social care. In Part III, we show how, depending on their design and deployment, and the framework in place to protect human rights, new and emerging technologies can pose significant risks to older people's enjoyment of human rights or enhance their autonomy and dignity, supporting them to live independently and participate in the community, moving away from models of care based on residential and nursing homes.

In Part IV, we set out our conclusions. Central to our findings is that significant work is needed to first understand, particularly from the perspective of older people as a diverse group, whether and how new and emerging technologies can improve later life, including in the context of social care. We find that the chances of new and emerging technologies contributing to the advancement and enjoyment of rights will be greatly enhanced, if they are introduced into social care environments that assume a rights-based approach to care. We therefore suggest that securing a rights-based approach to care should be prioritised as part of a wider commitment to grounding the design, development, and deployment of new and emerging technologies in social care in human rights.¹⁰

The Impact of the Covid-19 Pandemic on the Role of New and Emerging Technologies in the Field of Social Care

Most of the research underpinning this report was conducted prior to the Covid-19 global pandemic and the steps taken by states to prevent, treat, and control the spread of the virus. It is now sadly clear that the pandemic has had a terrible toll among those drawing on social care, and in particular those residing in residential care homes, which have been at the 'epicentre' of the pandemic in a number of (but not all) countries.¹¹ While equivalent evidence is unavailable regarding levels of infection and mortality among those receiving domiciliary care, statistics published by the Office of National Statistics in the UK report that 58 per cent of all who died from Covid-19 in England and Wales between March 2020 and March 2022 were disabled

¹⁰ McGregor et al (n6).

¹¹ The Long Term Care responses to Covid-19 research project estimates that on average the share of all COVID-19 deaths that were care home residents is 41% (based on 22 countries).

Adelina Comas-Herrera, Joseba Zalakaín, Elizabeth Lemmon, David Henderson, Charles Litwin, Amy T. Hsu, Andrea E. Schmidt, Greg Arling Florian Kruse and Jose-Luis Fernández,

'Mortality Associated With COVID-19 In Care Homes: International Evidence', International Long Term Care Policy Network February 2021,21, [https://ltccovid.org/wp-](https://ltccovid.org/wp-content/uploads/2021/02/LTC_COVID_19_international_report_January-1-February-1-1.pdf)

[content/uploads/2021/02/LTC_COVID_19_international_report_January-1-February-1-1.pdf](https://ltccovid.org/wp-content/uploads/2021/02/LTC_COVID_19_international_report_January-1-February-1-1.pdf).



people.¹² The ONS concludes that ‘it can be inferred that a large part (but not all) of the increased risk (of death from Covid-19) is because disabled people are disproportionately exposed to a broad range of generally disadvantageous circumstances compared with non-disabled people’. This includes the greater likelihood of living in communal facilities and of being in close contact with ‘keyworkers’ (which includes care-workers).

In many parts of the world, those falling into ‘at risk’ categories, which includes many older people, have at different points in time during the pandemic been advised to adopt the strictest measures to avoid exposure to the virus, such as by ‘shielding’ by not leaving home and by keeping their contact with others to an absolute minimum.¹³ This has posed significant challenges with respect to care and support, including how to ensure continuity of human-to-human care and support (both formal and informal) while minimising the risk of infection and coping with care staff absence through sickness; how to manage the admission of new residents to care and nursing homes, including those discharged from hospital; and how to ameliorate the social isolation that results from ‘social distancing’ measures between residents, those being supported in their own homes or other settings, with families and the outside world, and between those living within care settings.¹⁴ When ‘lockdown’ measures have eased, it has also been the case that those most susceptible to the disease have faced ongoing risks and attendant restrictions that impede their autonomy, participation and connection with the wider community, including with their families.

In this context, technology has played a new or expanded roles. For example, communications technologies have played a critical role in enabling everyone who has access to them, including older people, to stay in touch with family, friends, and their communities.¹⁵ Some older people are using such technology for the first time with a surge in uptake. However, the pandemic has also underlined ongoing digital divides which have

12 Office for National Statistics, Updated estimates of coronavirus (COVID-19) related deaths by disability status, England: 24 January to 9 March 2022 (9 May 2022).

13 For example, National Health Service, ‘People at Higher Risk from Coronavirus’, <https://www.nhs.uk/conditions/coronavirus-covid-19/people-at-higher-risk/>.

14 UN Secretary General, ‘Policy Brief: The Impact of COVID-19 on Older Persons’ (May 2020), <https://www.un.org/development/desa/ageing/wp-content/uploads/sites/24/2020/05/COVID-Older-persons.pdf>; WHO, ‘Policy Brief: Preventing and Managing COVID-19 across Long-Term Care Services’ (24 July 2020), https://www.who.int/publications/i/item/WHO-2019-nCoV-Policy_Brief-Long-term_Care-2020.1; UN Department of Economic and Social Affairs, ‘Policy Brief No 68: COVID-19 and Older Persons: A Defining Moment for an Informed, Inclusive and Targeted Response’ (May 2020), https://www.un.org/development/desa/ageing/wp-content/uploads/sites/24/2020/05/PB_68.pdf.

15 Gemma Wilson et al, *Connecting with others during Covid 19: Older adults use of social media and visual tools* (2020) https://www.ucl.ac.uk/psychiatry/sites/psychiatry/files/blog_how_can_technology_impact_social_connection_for_older_adults_during_covid.pdf

meant that many older people have been unable to access digital technologies during the pandemic.¹⁶ The divides persist at the most basic level of access to the internet and affordable data and devices, inaccessible technology for people with certain disabilities, as well as low levels of data literacy, meaning that many others are cut off from the world, and have been unable to access basic services, such as food and healthcare, due to a lack of data.¹⁷ Moreover, in the UK, many residential care homes, in which people have been enduring significant levels of isolation, did not have devices available to enable residents to videoconference with friends and relatives at the start of the pandemic. Some acquired them via donations¹⁸ and national or local government sponsored schemes.¹⁹ There is also some evidence of people accessing health appointments via teleconferencing using these same tablets and computers, including those living in care homes.²⁰

The early stages of the Covid-19 pandemic also witnessed an exponential growth in mutual aid groups, using internet-based communications technologies, websites and applications to reach (or to coordinate the reaching of) otherwise isolated local people and families and to organize mutual support with issues such as shopping and prescriptions during the crisis.²¹ This indicates opportunities to harness technology to marshal and organise informal resources and support beyond those funded directly by the state, which may prove invaluable during the coming years of demographic change and fast growing need for social care. Moreover, it speaks to the potential for technology to help build social capital and to strengthen, rather than weaken, community ties.

16 John Roesse, 'COVID-19 Exposed the Digital Divide. Here's How We Can Close It', World Economic Forum, World Economic Forum January 2021, <https://www.weforum.org/agenda/2021/01/covid-digital-divide-learning-education/>.

17 Annie Kelly, 'Digital Divide 'Isolates and Endangers' Millions Of UK's Poorest', *The Guardian* (April 2020) <https://www.theguardian.com/world/2020/apr/28/digital-divide-isolates-and-endangers-millions-of-uk-poorest>.

18 See: Kings Fund (2021) [Shaping the future of digital technology in health and social care](#) at 38.

19 Department of Health and Social Care, 'NHS Works With Tech Firms To Help Care Home Residents And Patients Connect With Loved Ones' (9 April 2020), <https://www.gov.uk/government/news/nhs-works-with-tech-firms-to-help-care-home-residents-and-patients-connect-with-loved-ones>.

20 Centre for Ageing Better, 'How Barnsley Is Using Recycled Tech To Support Its Local Care Homes', <https://www.ageing-better.org.uk/case-studies/how-barnsley-using-recycled-tech-support-local-care-homes>

21 Emma O'Dwyer, 'COVID-19 Mutual Aid Groups have the Potential to Increase Intergroup Solidarity –but can they actually do so?', *LSE British Politics and Policy Blog* (June 2020), <https://blogs.lse.ac.uk/politicsandpolicy/covid19-mutual-aid-solidarity/>.



The virus continues to present major challenges concerning the organisation and delivery of care and support, both in care settings and in people's own homes. Longer term, it seems likely that the impact of the pandemic on those receiving and those providing care and support, coupled with the major social and economic impact of the pandemic, will presage major reforms to the way care and support is organised, delivered and consumed. Indeed, reform proposals are being consulted on in England²² and Scotland²³ and the European Commission has announced publication of an EU Care Strategy in 2022.²⁴ All envisage an enlarged role for digital and other technology in the delivery of social care reform. In this report, we reflect that the impact of the pandemic on those drawing on and delivering social care, its legacy and ongoing effects and the role technology has played and is increasingly playing confirms, rather than challenges, much of our existing analysis, conclusions and recommendations.

Definitions:

Many of the terms used in this report to describe specific technologies or to group together different technologies are contested and vary depending on their disciplinary, policy or practical context as well as how they are referred to in the media or popular culture. Notwithstanding these debates, the following explains our use of particular terms in this report:

Older people: we use the World Health Organization's categorisation of older people as people aged 60 and over.²⁵

Social care: we have used this term to refer to all forms of personal care and other practical assistance for adults who need targeted support with daily living. Depending on the circumstances, this may be provided informally without payment, or formally by paid professionals. As discussed in this report, we do not limit our definition of social care to 'maintenance' but all support that is necessary to realise a rights-based model of

²² Department for Health and Social Care UK, *People at the Heart of Care: adult social care reform white paper* (2021) <https://www.gov.uk/government/publications/people-at-the-heart-of-care-adult-social-care-reform-white-paper>

²³ Scottish Government, *A National Care Service for Scotland* (2021) <https://consult.gov.scot/health-and-social-care/a-national-care-service-for-scotland/>

²⁴ European Commission, *European Care Strategy* (2022) https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/13298-European-care-strategy_en

²⁵ WHO, Decade of Healthy Ageing (n3).



social care, thus enabling older people to live a full life with autonomy and dignity and to fully participate and be included in the community.

New and emerging technologies: we use ‘new and emerging technologies’ as a catch-all phrase to describe a range of technologies used in the care of older people. These can include:

- **internet enabled devices**, such as lap and desktops, tablets, and smart phones;
- the **Internet of Things** as ‘a system of interrelated computing devices, mechanical and digital machines, objects, animals or people that are provided with unique identifiers (UIDs) and the ability to transfer data over a network without requiring human-to-human or human-to-computer interaction’.²⁶
- **Smart home technology** refers to the use of devices in the home that connect via a network that can be remotely monitored, controlled, or accessed and provide services that respond to the perceived needs of the users.²⁷
- **Biometric technologies** used to identify a person based on, for example, voice or facial recognition²⁸ as well as motion sensors;
- **Wearable technologies**, such as technologies to monitor and track activity and health.²⁹

Some of these technologies may be enabled by **artificial intelligence (‘AI’)**, which like new and emerging technologies, is a catch-all phrase without an agreed definition.³⁰ The European Commission has defined AI as:

Artificial intelligence (AI) systems are software (and possibly also hardware) systems designed by humans that, given a complex goal, act in the physical or digital dimension by perceiving their

²⁶ Alexander Gillis, ‘Internet of Things (IoT)’, IOT Agenda <https://internetofthingsagenda.techtarget.com/definition/Internet-of-Things-IoT>

²⁷ The Joint Institute for Innovation Policy (JIIP), Joanneum Research Forschungsgesellschaft mbH, Fundación Tecnalia Research & Innovation, VTT Technical Research Centre of Finland, KPMG AG, ‘Study On Mapping Internet Of Things Innovation Clusters In Europe’, European Commission 2019, 35, <https://aioti.eu/wp-content/uploads/2020/02/IoTInnovationClustersFinalReportFINALpdf>

²⁸ Digital Transformation Monitor, ‘Biometrics Technologies: A Key Enabler for Future Digital Services’, European Commission January 2018, 2, https://ec.europa.eu/growth/toolsdatabases/dem/monitor/sites/default/files/Biometrics%20technologies_v2.pdf.

²⁹ Mary Rodgers, Gad Alon, Vinay Pai and Richard S Conroy, ‘Wearable Technologies for Active Living and Rehabilitation: Current Research Challenges and Future Opportunities’, 6 Journal of Rehabilitation and Assistive Technologies Engineering 2019, 1-9, 1, <https://journals.sagepub.com/doi/pdf/10.1177/2055668319839607> accessed 15 February 2021.

³⁰ Ryan Calo, ‘Artificial Intelligence Policy: A Primer and Roadmap’, 51 *UC Davis Law Review* 399 (2017), at 404.



environment through data acquisition, interpreting the collected structured or unstructured data, reasoning on the knowledge, or processing the information, derived from this data and deciding the best action(s) to take to achieve the given goal. AI systems can either use symbolic rules or learn a numeric model, and they can also adapt their behaviour by analysing how the environment is affected by their previous actions. As a scientific discipline, AI includes several approaches and techniques, such as machine learning (of which deep learning and reinforcement learning are specific examples), machine reasoning (which includes planning, scheduling, knowledge representation and reasoning, search, and optimization), and robotics (which includes control, perception, sensors and actuators, as well as the integration of all other techniques into cyber-physical systems.³¹

New and emerging technologies may be used to analyse and process data, with **data analytics** referring to the analytical capability to bring together different data sets to reveal patterns, trends, and associations, especially relating to human behaviour and interactions.³²

They may also be used to fully or partially **automate** processes, procedures or decisions without human involvement or only with human supervision or review.³³ Automation will often be achieved through the use of **machine learning algorithms**. Machine learning concerns the capacity of computers to learn without being programmed to carry out specific tasks, although the current capacity for machine learning technologies to independently learn or carry out specific tasks remains at a relatively rudimentary stage.³⁴

31 European Commission High-Level Expert Group on Artificial Intelligence, 'A Definition of Artificial Intelligence: Main Capabilities and Scientific Disciplines' (8 April 2019), 6, <https://ec.europa.eu/digital-single-market/en/news/definition-artificial-intelligence-main-capabilities-and-scientific-disciplines>.

32 Council of Europe, Committee of Experts on Internet Intermediaries (MSI-NET), 'Algorithms and Human Rights: Study on The Human Rights Dimensions of Automated Data Processing Techniques and Possible Regulatory Implications' (March 2018), 6, <https://edoc.coe.int/en/internet/7589-algorithms-and-human-rights-study-on-the-human-rights-dimensions-of-automated-data-processing-techniques-and-possible-regulatory-implications.html>.

33 Information Commissioner's Office, 'Big Data, Artificial Intelligence, Machine Learning and Data Protection Version 2.2' (September 2017), 7-8, <https://ico.org.uk/media/for-organisations/documents/2013559/big-data-ai-ml-and-data-protection.pdf>.

34 The Royal Society, 'Machine learning: the power and promise of computers that learn by example' (April 2017) <https://royalsociety.org/~media/policy/projects/machine-learning/publications/machine-learning-report.pdf>.



II. CURRENT AND FUTURE TRAJECTORIES FOR SOCIAL CARE AND NEW AND EMERGING TECHNOLOGIES

The evolution of technology in the field of social care is being driven by, and is contributing to, wider social, economic, political, legal, technological, and environmental change. In this part of the report, we first discuss the growing gap between the supply and demand for care, brought about by ageing populations with a diverse range of health needs, social change, and under-investment in social care in many states. We then explain how the conceptualisation of social care is evolving from a narrow transactional (and often paternalistic) concept of care to a rights-based, social model, sometimes linked to concepts such as ‘active ageing’.³⁵

The implementation of a social model of care requires the recognition of older people as rights-holders. It not only entails those offering care and support addressing health needs but also involves providing older people with support to make autonomous decisions about their care and support and where and how they live as well as supporting them to participate and be included in the community. A key dimension to the social model of care is a move away from institutionalisation and congregate models of care to support people to live independently in the community.³⁶ We observe how resource-constraints and political positioning can constrain the realisation of a rights-based approach to social care. We argue that it is critical to understand and analyse the introduction of new and emerging technologies in this context in order to assess whether they offer a means to accelerate the realisation of a rights-based model to social care or risk returning – or worsening – a traditional, institutional approach to social care. Finally, we reflect upon the different ‘entry points’ via which new and emerging technologies are introduced into social care and their different functions.

³⁵ World Health Organization (WHO), ‘Active Ageing: A Policy Framework’ (2002) WHO/NMH/NPH/02.8,

https://apps.who.int/iris/bitstream/handle/10665/67215/WHO_NMH_NPH_02.8.pdf;jsessionid=6F8ED226F2CD697E5CEE9DAFD53A599?sequence=1 (defining active ageing as ‘the process of optimizing opportunities for health, participation and security to enhance quality of life as people age’).

³⁶ Camilla Parker, ‘A community for all: implementing Article 19. A guide for monitoring progress on the implementation of Article 19 CRPD’, *Open Society Foundation* (December 2011), https://www.opensocietyfoundations.org/sites/default/files/community-for-all-checklist-20111202_0.pdf.



A. Populations are ageing, increasing the need for social care

Globally, populations are ageing. According to the World Health Organization (WHO), the two key drivers of ageing populations are first, increased life expectancy, including increased survival into adulthood, and more recently increased survival in old age, and second, declining fertility.³⁷ The WHO asserts that:

population ageing will dramatically increase the proportion and number of people needing social care in countries at all levels of development. This will occur at the same time as the proportion of people at younger ages who might be available to provide this care will be falling, and the role of women, who have until now been the main care providers, is changing.³⁸

Developing effective policies to meet the needs of ageing populations therefore constitutes a priority for states across the globe.

In many states, investment of public resources in social care has not kept pace with demand, widening the gulf between publicly funded care and that which is purchased, arranged, or facilitated by older people and their families.³⁹ This can be challenging as while greater life expectancy has increased the chances of different generations within a family being alive at the same time, these generations are now more likely to live separately, with the proportion of older people living alone rising dramatically.⁴⁰ Related, a major trend over the past 50 years has been a global demographic shift from rural to urban living.⁴¹ While it has become easier for young generations to migrate to areas of growth, this can result in older generations being left without the traditional family structures to which they may have previously turned for support.⁴² Moreover, as noted by the WHO, a move away from women as traditional caregivers, means that even where families live close

³⁷WHO, 'World Report on Ageing and Health' (2015), 43-48, https://apps.who.int/iris/bitstream/handle/10665/186463/9789240694811_eng.pdf?sequence=1.

³⁸ Ibid at 69.

³⁹ Ibid at 131; Francesca Colombo, Ana Llana-Nozal, Jerome Mercier and Frits Tjadens, 'Help Wanted? Providing and Paying for Long-Term Care', OECD Publishing 2011, 38, <https://www.oecd.org/health/health-systems/help-wanted-9789264097759-en.htm>.

⁴⁰ WHO, 'World Report on Ageing and Health' (n37), at 12.

⁴¹ Ibid.

⁴² Ibid.



together, a family member may not be available to offer support,⁴³ although globally, women continue to play a central – and often unrecognised and unpaid – role in providing such support.⁴⁴ It is in this context of increasing demand accompanied by under-investment in state-supported care and support that the role of new and emerging technologies is often being shaped.

B. New paradigms are challenging traditional ideas of social care

Historically, social care has often operated within a paradigm of paternalistic welfare or charity. As Scottish Care noted in its report, *Tech Rights: Human Rights, Technology and Social Care*, '[t]he care relationship is often portrayed as a passive exchange between the "carer" and the "cared for"'.⁴⁵ The WHO has also observed that, '[a]lthough there are outstanding exceptions, significant threats to the quality of care come from outdated ideas and ways of working, which often focus on keeping older people alive rather than on supporting dignified living and maintaining their intrinsic capacity'.⁴⁶ This can mean that care is sometimes limited to attending to older people's 'life and limb' needs such as bathing, eating, and dressing, but not on supporting the maintenance or establishment of social connections, pursuing interests, or inclusion and value in society. The WHO highlights the risks these outdated approaches present to older people, including abuse and the use of physical and chemical restraint of persons living with dementia, as well as burn out experienced by family caregivers.⁴⁷

Models of care can also narrowly focus on health needs rather than the full range of support older people require to live a dignified life. Care and support needs related to health are clearly critical and can include support for challenges with mobility and dexterity; risk of falls and other accidents; risk of harm to self or others; challenges to maintaining hygiene; maintaining nutrition; avoiding dehydration; and mental ill-health. Increasingly common is so-called 'multimorbidity' where people experience numerous conditions

43 Ibid.

44 See Max Lawson, Anam Parvez Butt, Rowan Harvey, Diana Sarosi, Clare Coffey, Kim Piaget, Julie Thekkudan, 'Time to Care: Unpaid and underpaid care work and the global inequality crisis', Oxfam (January 2020), <https://www.oxfam.org/en/research/time-care>

45 Macaskill (n7), at 27.

46 WHO, 'World Report on Ageing and Health' (n37), at 133.

47 Ibid.



simultaneously.⁴⁸ However, the WHO points out that ‘the presence of these health conditions says nothing about the impact they may have on an older person’s life’.⁴⁹ As discussed in this section, the availability and quality of social care and support; adaptive technologies; accessible housing; strong and supportive social networks; and income and material wealth all serve to mediate the impact of health conditions on older people’s opportunities to maintain choice, control, and dignity in their lives.⁵⁰

The global disability rights movement has challenged paternalistic models of social care, which often result in the denial of basic human rights.⁵¹ In particular, the movement has sought to direct policy and action away from a focus on medical intervention, care, and charity towards securing full inclusion and participation of persons with disabilities, including older people with disabilities, in society.⁵² To these ends, the UN Convention on the Rights of Persons with Disabilities 2006 (UN CRPD) heralds a paradigm shift in thinking about both disability and social care, requiring states to affect a transition from ‘institutional care’ to ensuring persons with disabilities can live independently and be included in the community.⁵³

The UN CRPD is founded upon what Theresia Degener has called the ‘human rights model of disability’,⁵⁴ defining persons with disabilities as including, ‘those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’.⁵⁵ In its report on Health and Ageing, the WHO adopts a similar definition, noting that, ‘functioning is determined not just by assessing physical and mental capacities but also by the interactions each of us has with the environments we inhabit across our lives’.⁵⁶

48 Ibid, at 26.

49 Ibid, at 26.

50 Ibid, at 26-27.

51 James Charlton, *Nothing About Us Without Us – Disability, Oppression and Empowerment* (2000), at 128.

52 Ibid, at 17.

53 UN Committee on the Rights of Persons with Disabilities (n4).

54 Theresia Degener, ‘A human rights model of disability’ in Peter Blanck and Eilionóir Flynn (eds), *Routledge Handbook of Disability Law and Human Rights* (2016)

55 CRPD, Article 2.

56 WHO, ‘World Report on Ageing and Health’ (n37), at 26.



These environmental influences on health in older age may take many forms, including the broad policies that affect us, the economic situation, a community's attitudes or social norms, the physical characteristics of the natural and built environment, the social networks that we can draw on, and the technologies that may be increasingly commonplace. These factors shape both the physical and mental capacities we have at any time (for example, by influencing our available options and our choice about health behaviours), and whether, no matter our real or perceived mental capacity, we can do the things we want to do. An understanding of the role of these wide-ranging contextual factors must be central to any strategy aimed at fostering health in older age.

The process of implementing the UN CRPD (and of promoting healthy ageing) can therefore best be understood as one of social change. The Convention presages a need for radical reform of laws, policies, institutions, and practice of immediate relevance to the field of health and social care including:

- Article 5 on equality and non-discrimination
- Article 9 on accessibility
- Article 12 on equal recognition before the law
- Article 14 on liberty and security of the person
- Article 19 on living independently and being included in the community
- Article 20 on personal mobility
- Article 26 on habilitation and rehabilitation

New social movements, including of persons living with dementia, have been inspired by the disability rights movement to challenge stereotypes and practices that deny their human rights.⁵⁷ The disability rights movement has also focused greater attention on the human rights of older people, including in social care, and assessments of whether new approaches are needed to ensure that these rights are enjoyed in practice.⁵⁸ The UN Independent Expert on the enjoyment of all human rights by older people has asserted that 'support (for older people) should be available as a means to expand opportunities and not as a method of

⁵⁷ See, for example, Dementia Alliance International, <https://t.co/QdZrIKoceo?amp=1>

⁵⁸ Frederic Megret, 'The Human Rights of Older Persons: A Growing Challenge', 11 *Human Rights Law Review* 37 (2011), at 39.

maintenance'.⁵⁹ A UN Open-Ended Working Group on Ageing was also established in 2010 to 'consider the existing international framework on the human rights of older people and identify possible gaps and how best to address them, including by considering, as appropriate, the feasibility of further instruments and measures'.⁶⁰ This includes the possibility of the adoption of a dedicated treaty or international instrument on the human rights of older people, similar in approach to the UN CRPD.⁶¹ Such instruments exist to promote equality and non-discrimination in the enjoyment of existing human rights by hitherto overlooked and marginalised groups such as disabled and older people. They are critical to 'articulating how existing law applies to groups who are not able to enjoy their rights effectively in practice' and in pointing to the specific action states must take to implement human rights in practice.⁶²

In its World Report on Ageing and Health, the WHO asserts that '[t]here are many justifications for devoting public resources to improving the health of older populations. The first is the human right that older people have to the highest attainable standard of health'.⁶³ It goes on to assert that,

no country can afford not to have a comprehensive system of long-term care. (..) The central goal of these systems should be to maintain a level of functional ability in older people who have or are at high risk of significant losses of capacity, and to ensure that this care is consistent with their basic rights, fundamental freedoms and human dignity. This will require acknowledging their continuing aspirations to well-being and respect.⁶⁴

⁵⁹ 'Report of the Independent Expert on the enjoyment of all human rights by older persons' (n8), at §48.

⁶⁰ Open-Ended Working Group on Ageing, <https://social.un.org/ageing-working-group/>

⁶¹ HelpAge International, 'Why it's time for a convention on the rights of older people' (2009), 6, <https://rightsofolderpeople.org/wp-content/uploads/2020/07/Why-it-is-time-for-a-convention-on-the-rights-of-older-people.pdf>; Bridget Sleaf, Robin Allen, Andrew Byrnes, Israel (Issi) Doron, Nena Georgantzi and Bill Mitchell, 'Time For A UN Convention On The Rights Of Older Persons', HelpAge International, Cloisters Chambers, Australian Human Rights Institute, University of Haifa, AGE Platform Europe, Community Legal Centres Australia (August 2020), 3, https://www.age-platform.eu/sites/default/files/Discussion_Paper_COVID-19_Time_for_a_UN_Convention-Aug2020.pdf.

⁶² Lorna McGregor, 'Looking to The Future: The Scope, Value and Operationalization of International Human Rights Law', 52 *Vanderbilt Journal of Transnational Law* 1281 (2019), at 1281.

⁶³ WHO, 'World Report on Ageing and Health' (n37), at 14.

⁶⁴ *Ibid* at 215.



A rights-based model of social care is therefore not about ‘maintaining’ a person or the transactional provision of food, medication, getting up or going to bed. Rather, it starts from a position of human dignity, fairness, equality, inclusion, participation, and empowerment. It underscores the agency of older people to be included in the community, to be in control of decisions about their lives and the role of support in achieving their life goals, and to be able to claim their human rights.⁶⁵ This requires not only a rights-based approach to health and care but also inclusion and participation in the community on an equal basis with others,⁶⁶ and transition from institutional care to independent living, the foundations of which are autonomy and independence in decision-making with support⁶⁷ and the liberty and security of the person.⁶⁸

These shifts, from the individual to the systemic; from understanding ageing, health, and disability as biologically determined to having a strong social component; and to addressing those social components as a matter of respecting, protecting, and ensuring human rights are fundamentally important in any analysis of the potential human rights implications of new and emerging technologies in the field of social care.

C. What are the goals of a rights-based model of social care?

As noted above, in line with the UN CRPD, social care cannot be conceived of as only about health needs but encompasses the role, inclusion, and value of older people in society. The WHO recommends that states focus on optimising the ‘intrinsic capacities’ of people as they age, their ‘functional ability’, and the environment.⁶⁹ It defines ‘intrinsic capacity’ as the ‘composite of all the physical and mental capacities of an individual’ while ‘functional ability’ comprises the health-related attributes that enable people to be and to do what they have reason to value.⁷⁰ In its Baseline Report published in 2020, the WHO states that the environment includes products, equipment, and technology that facilitate movement, sight, memory, and daily functioning and that

65 Ruth Townsley, Linda Ward, David Abbott and Val Williams, ‘The Implementation Of Policies Supporting Independent Living For Disabled People In Europe: Synthesis Report’, Academic Network of European Disability Experts (ANED) November 2009, amended January 2010, 8,

https://www.researchgate.net/publication/301359043_The_implementation_of_policies_supporting_independent_living_for_disabled_people_in_Europe_synthesis_report.

66 See UN Committee on the Rights of Persons with Disabilities (n4).

67 See UN Committee on the Rights of Persons with Disabilities, (n2).

68 See UNGA, ‘Guidelines on The Right to Liberty and Security of Persons with Disabilities’ (n3).

69 WHO, ‘World Report on Ageing and Health’ (n37).

70 Ibid.



the development of enabling, age-friendly environments that optimize functional ability is another key factor to healthy ageing.⁷¹ In its World Report on Ageing and Health, the WHO lists the following as priorities that have been identified by older people: ‘a role or identity; relationships; the possibility of enjoyment; autonomy (being independent and being able to make their own decisions); security; and the potential for personal growth’.⁷² It explains functional abilities deemed to be critical to people maintaining or achieving these are being able to: ‘move around; build and maintain relationships; meet their own basic needs; learn, grow and make decisions; contribute’.⁷³

In the field of disability rights, a particular focus is on bringing about a system-wide transition from institutional care to a model of interdependence through the supports necessary to enable people with disabilities to live independently and have an active role in community life. The UN Committee on the Rights of Persons with Disabilities has advised that implementation of Article 19 of the Convention requires states to close down existing institutional care facilities; to stop supporting the development of new institutional care facilities; and to develop community-based support, centred on individual choice and control in its place.⁷⁴ The European Expert Group on the Transition from Institutional to Community-based Care defines de-institutionalisation as:

a process which includes: (1) The development of high quality, individualised services based in the community, including those aimed at preventing institutionalisation, and the transfer of resources from long stay residential institutions to the new services in order to ensure long-term sustainability. (2) The planned closure of long-stay residential institutions where children, people with disabilities (including people with mental health problems), homeless people and older people live, segregated from society, with inadequate standards of care and support, and where enjoyment of their human rights is often denied. (3) Making mainstream services such as education and training, employment, housing, health and transport fully accessible and available to all children and adults with support needs.⁷⁵

71 WHO, Decade of Healthy Ageing (n3).

72 WHO, World Report on Ageing and Health (n37), at 29-30.

73 Ibid, at 30.

74 UN Committee on the Rights of Persons with Disabilities, (n4).

75 European Expert Group on the transition from institutional care to community-based care, ‘Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care’ (2014), 11, <http://enil.eu/wp-content/uploads/2014/07/Toolkit-07-01-2014-WEB.pdf>.



It is important to note that there is no consensus among different stakeholder groups as to what constitutes ‘institutional care’, with some groups representing disabled people being opposed to all forms of congregate living, while others support residential care homes for those who choose to live in them.⁷⁶ Within the policy sphere on ageing, there has been an increasing focus on ‘ageing in place’, which refers to the ability of older people to live in their own home and community safely, independently and comfortably.⁷⁷ While this is generally viewed as beneficial to older people, the WHO has noted that,

it may not be the prime goal for isolated older people, for those with high unmet needs for care and inappropriate housing, or for those living in unsafe or less than supportive neighbourhoods ... Recent advances in developing new forms of assisted living and nursing-home care provide many alternatives to the stereotypical choice between living at home or in a home. These alternatives can enable an older person to thrive in ways that might not be possible in their original community⁷⁸

Alongside this shift, the UN CRPD anticipates the reform of law, policy and practice concerning legal personhood and autonomy, in particular the transition from ‘substitute decision making’ regimes, such as plenary guardianship, to granting all persons full legal capacity and instituting ‘supported decision-making’ regimes.⁷⁹ It also requires the reform of law, policy, and practice that permits deprivation of liberty or security of the person on grounds of disability.⁸⁰ Both areas have significant implications with respect to care and support for older people, especially those with dementia.

D. Challenges in implementation

Despite these significant shifts at the level of principle, law and policy, there is evidence that other imperatives drive practice on the ground and therefore present obstacles to fully embedding a rights-based approach to

76 For discussion see Neil Crowther, ‘The Right to Live Independently and to be Included in the Community in European States - ANED Synthesis Report’, European network of academic experts in the field of disability (ANED) (May 2019), <https://www.disability-europe.net/theme/independent-living>.

77 Janine Wiles, Annette Leibing, Nancy Guberman, Jeanne Reeve and Ruth Allen, ‘The Meaning of “Ageing in Place” to Older People’, *The Gerontologist* 357 (2011), at 357, https://www.researchgate.net/publication/284814677_The_meaning_of_ageing_in_place_to_older_people.

78 WHO, ‘World Report on Ageing and Health’ (n37), at 36.

79 UN Committee on the Rights of Persons with Disabilities, (n2).

80 UNGA, ‘Guidelines on the Right to Liberty and Security of Persons with Disabilities’ (n3).



social care. In particular, the orientation of public policy towards cost-containment in many countries where long-term care is concerned is a significant challenge. As highlighted by the Centre for Ageing Better, age-related stereotypes typically portray longevity as a threat rather than an opportunity, and older people as a growing social and economic burden rather than long term care as an investment, which promotes prejudice and discrimination.⁸¹

While some social attitudes have become more progressive, ageism remains pervasive and structural in many societies. The WHO advises that successful action to promote health and wellbeing ‘cannot be based on outdated conceptualizations of older people as burdens or on unrealistic assumptions that older people today have somehow avoided the health challenges of their parents and grandparents. Rather, it demands an acceptance of the wide diversity of the experience of older age, acknowledgement of the inequities that often underlie it, and an openness to ask how things might be done better’.⁸² As one interviewee suggested ‘a care paradigm, rather than support paradigm, dominates debates about care and older people and this constrains thinking about technology’.⁸³

E. Trends in technology and social care

The role of new and emerging technologies is increasingly prominent in debates about the future of care and support for older people and persons with disabilities. With respect to care specifically, the UN Independent Expert on the enjoyment of all human rights by older persons reported to the UN Human Rights Council that:

[a]ssistive devices and robotics can compensate for physical weaknesses by enabling older people to eat, bathe, shop or get out of bed on their own. They can enhance their capacity to self-manage daily activities, such as shopping or cleaning, without being dependent on caregivers or family members. Smart living environments, including sensors and other applications that monitor older people’ health

⁸¹ Centre for Ageing Better, ‘Dodderly but Dear? Examining Age Related Stereotypes’ (2020), <https://www.ageing-better.org.uk/publications/dodderly-dear-examining-age-related-stereotypes>; Angela Kydd, Anne Fleming, Sue Gardner, and Trish Hafford-Letchfield, ‘Ageism in The Third Age’ in Liat Ayalon and Clemens Tesch-Römer (eds), *Contemporary Perspectives on Ageism: 19 International Perspectives on Aging* (2018), at 115; John Hudson, Marta Orviska and Jan Hunady, ‘People’s Attitudes to Robots in Caring for the Elderly’, 9

International Journal of Social Robotics 199 (2017), at 199.

⁸² WHO, ‘World Report on Ageing and Health’ (n37), at 218.

⁸³ Interview 2 (14 October 2019).

and behaviour, and help prevent hazards, can enable them to live independently in their own homes and avoid entering residential settings. Electronic bracelets, assistance through a global positioning system (GPS), technology-augmented travel applications and other accessible solutions allow older people, including those with cognitive impairments, to travel and move about alone. Memory and communication applications can support older people's cognitive capacity and by extension their independent living.⁸⁴

The WHO highlights how 'the Internet can allow continued connection with family despite distance, or access to information that can guide an older person's self-care or provide support to caregivers. Assistive devices, such as hearing aids, are more functional and more affordable than in the past, and wearable devices provide new opportunities for health monitoring and personalized health care'.⁸⁵

An important finding of our study, with significant implications for both future analysis and action, is the multiple 'entry points' of new and emerging technologies into the sphere of social care for older people. This includes the origins of technologies, how they come to be utilised in the context of care, and the motivations lying behind their development or use.

1. Age tech v repurposing general use technology

A first important distinction is between technologies developed for social care (often referred to as 'age tech'), and those that have been harnessed to these ends. On the one hand, a large market exists for technology that is **designed and marketed specifically for the purposes of health and social care**, for example, therapeutic robotic pets for older people, including those with dementia, or facial recognition software aimed at detecting pain in people who face difficulties communicating or being understood.⁸⁶

On the other hand, **technology aimed at general markets may be repurposed to the ends of care**, including through connectivity. For example, smart speakers may be used or provided to people with dementia as a

⁸⁴ Report of the Independent Expert on the enjoyment of all human rights by older persons' (n8), at §26.

⁸⁵ WHO 'Summary: World Report on Ageing and Health' (2015) WHO/FWC/ALC/15.01, 10, https://apps.who.int/iris/bitstream/handle/10665/186468/WHO_FWC_ALC_15.01_eng.pdf?sequence=1.

⁸⁶ Suzy Taherian, 'Silver Tech' is the young hot growing tech trend for seniors' *Forbes* (15 July 2020).



memory aid; or smart home technology may be installed to enable family members to monitor older relatives for falls and other accidents at a distance.

This distinction represents a broader reality that ‘social care’ is not, for many, a single identifiable ‘system’ or sector, but a product of multiple actors interacting within an ecosystem of support. Hence, there cannot be one single ‘fix’ or initiative when it comes to the question of ensuring the human rights compliance of new and emerging technologies in the sphere of social care.

2. How new and emerging technologies end up in social care

The second set of distinctions concern the entry of these technologies into the sphere of social care. While we are not able to quantify the current extent of technological use, and in many cases, technology will enter via several channels, the following broad categories can be identified:

Technology that is acquired or adapted by individuals or families either to address an identifiable care need, or as part of a wider utilisation of technologies for care and wellbeing: for example, smart meters, which allow people to control and regulate heating and lighting remotely or via AI-enabled technologies, or wearable fitness devices to monitor health and encourage exercise.

Technology that is commissioned by government bodies as a way to offer care or promote wellbeing: for example, local authorities that have invested in smart speakers for people with dementia;⁸⁷ the commissioning of community warden services that use wearable devices or other home sensors to detect falls;⁸⁸ and the use of machine learning algorithms to predict risk and as an aid to decision making.

Technology that is used to automate caregiving by care providers, improve performance and efficiency or acquired by care providers to enhance outcomes: for example, digitalisation of care plans and records, GPS tracking of care workers, use of home sensors in place of overnight care staff.⁸⁹

⁸⁷ For example, Norfolk Council looks at Alexa for social care <https://www.ukauthority.com/articles/norfolk-council-looks-at-alexa-for-social-care/>

⁸⁸ E.g. TSA (2022) Connecting TEC, UCR and Responder Services – the blueprint for integrated services Warrington Borough Council https://www.tsa-voice.org.uk/downloads/case_studies/warrington_case_study-_final.pdf

⁸⁹ See: <https://www.nhs.uk/key-tools-and-info/adult-social-care-digital-transformation/digitising-social-care-fund/>



Increasingly, we also must anticipate the capacity for different technologies, through their interaction with one another, and with humans, to co-create and achieve new possibilities that have not been imagined, designed, or programmed by humans.

As a result of the above, the diverse ways that new and emerging technologies are already being used and may be used in the future pose significant challenges with respect to accountability, regulation, and to citizen/consumer awareness and power.

3. Reasons for using new and emerging technologies in social care

A third distinction concerns the motivations that appear to lie behind the development or application of new and emerging technologies, often captured in the way their purpose and value is framed:

Efficiency and demand-centred: the case for investing in, developing, and using new and emerging technologies in the sphere of social care is frequently framed as one of mitigating the ‘growing costs’ of ageing societies, including by delivering efficiencies and managing anticipated gaps between the available workforce and demand for care.⁹⁰

Wellbeing-centred: In some instances, the case for investment, design, or use of new and emerging technologies is explicitly framed as enhancing wellbeing, though this appears less commonplace than arguments centred on efficiency and managing demand.⁹¹ The literature suggests that new and emerging technologies are being developed or used to meet a wide-range of goals in social care such as safeguarding; monitoring and well-being; companionship, stimulation and therapy; risk-prediction; management of care-delivery; and the connection of different technologies within a smart home. While some technologies are already being used or marketed for use in people’s own homes or other care settings, others appear either theoretical, or exist but with much less capability than popular discourse often suggests. Accordingly, it remains important in policy debates on social care to distinguish between technologies that are already available or currently at the research or development stage, and those which are imagined but unlikely to

⁹⁰ John Percival and Julienne Hanson, ‘Big brother or brave new world? Telecare and its implications for older people’s independence and social inclusion’, 26 *Critical Social Policy Ltd* 888 (2006), at 889.

⁹¹ Macaskill (n7), at 46.



emerge in the near future, and to carefully scrutinise claims about technological capabilities, particularly their capacity to replace certain human functions.

Safeguarding: New and emerging technologies are being developed and utilised to support the monitoring of people with care and support needs to ensure that they are safe, for example with respect to falls or seizures or people with dementia who may get lost, for example through lasers and tracking apps.⁹² AI-enabled technologies also offer new opportunities to prevent, detect, and bring the perpetrators of violence, exploitation, and abuse to justice. For example, facial, voice, or biometric recognition technologies can help a person to decide who to let into their home and can spot unusual patterns of spending on people's credit and debit cards, improving security. AI-enabled technologies can be developed to detect specific incidents of abuse or recognise patterns of behaviour that suggest a person may be experiencing physical or psychological abuse, albeit balanced against privacy.

Monitoring health and wellbeing: A significant area of growth with respect to new and emerging technologies in care concerns the remote and automated monitoring of health and wellbeing, including wearable devices, voice-based virtual assistants, facial recognition, and telerobots.⁹³ Several mobile phone applications and pillboxes have been introduced to remind older people to take medication, to monitor and assess whether it has been taken correctly, notify of upcoming appointments or care visits or to recommend activities to engage in throughout the day. Other technologies have been developed reportedly to analyse a person's face to detect pain.⁹⁴

92 Katherine Davis and Abbi Hobbs, 'Innovations in Adult Social Care' *UK Parliament Post* POSTnote 670 (May 2022)

93 Mary Rodgers, Gad Alon, Vinay Pai and Richard S Conroy, 'Wearable Technologies for Active Living and Rehabilitation: Current Research Challenges and Future Opportunities', 6 *Journal of Rehabilitation and Assistive Technologies Engineering* 1 (2019) at 1, <https://journals.sagepub.com/doi/pdf/10.1177/2055668319839607>

94 See Paul Dinsdale, 'From Pain Relief To Memory Prompts: The Apps Helping People With Dementia', *The Guardian* (November 2019), <https://www.theguardian.com/careers/2019/nov/20/from-pain-relief-to-memory-prompts-the-apps-helping-people-with-dementia>



Companionship, stimulation, and therapy: companion, therapeutic and assistive chatbots and robots are increasingly available.⁹⁵ Some of these technologies employ machine learning to learn about a person and to try to engage with them based on their interests and personality.

Virtual reality is already being explored as a way to simulate experiences for older people and persons with disabilities such as engaging in outdoor exercise or undertaking activities otherwise considered impossible or unsafe such as mountain-climbing.⁹⁶ Brain computer interface technology has also been combined with virtual reality to allow a person to operate an avatar in a virtual reality environment for the purposes of social interaction with other users.⁹⁷

Assistance with memory and decision-making: AI-enabled technologies are reportedly being trialled as memory aids for older people and in the context of supported decision-making, including for people with dementia.⁹⁸

Smart homes: The combination of ‘smart’ technologies within the domestic sphere, allying the ‘Internet of Things’ (IoT) to AI is sometimes referred to as ‘smart housing’ and is playing a growing role in supporting the independence of older people and persons with disabilities. As noted above, smart homes may be harnessed by older people and their families to support older people living in their homes or may be designed with social care specifically in mind.⁹⁹

95 Allyssia Alleyne, ‘Chat bots are becoming uncannily human. Can they be our friends?’, *CNN* (July 2020), <https://edition.cnn.com/style/article/tech-loneliness-replika-wellness/index.html>

96 Claudia Cahalane ‘8 ways virtual reality could transform the lives of disabled people’ *Ability Net* (2017) <https://abilitynet.org.uk/news-blogs/8-ways-virtual-reality-could-transform-lives-disabled-people>

97 Felix Putze, Athanasios Vourvopoulos, Anatole Lécuyer, Dean Krusienski, Sergi Bermúdez Badia, Timothy Mullen and Christian Herff, ‘Editorial: Brain-Computer Interfaces And Augmented/Virtual Reality’, 14 *Frontiers in Human Neuroscience* (2020), <https://www.frontiersin.org/articles/10.3389/fnhum.2020.00144/full>.

98 Reuters, ‘Virtual reality coronation takes dementia patients down memory lane’ (23 February 2018), <https://www.reuters.com/article/us-tech-dementia-vr-idUSKCN1G723Q>

99 Sarah Wray, ‘The real benefits of smart homes could be in social care’ *Cities Today* (28 April 2022); Clive Gilbert, ‘Smarter Homes for Independent Living’ *Policy Connect and All Parliamentary Group for Assistive Living* (28 April 2022).



Risk prediction and decision-making by public authorities and care providers: Some local authorities in the UK use machine learning algorithmic processes to identify and predict risk.¹⁰⁰ The use of automated decision-making technologies by public administrations and business is growing, including the semi-automation of application, assessment, and monitoring processes for financial and practical support for older and disabled people.

Management of care delivery: Many care providers already employ digital platforms to manage care delivery and to maintain records. Some use technologies to monitor and manage staff performance, using increasingly detailed and regimented scheduling platforms and tracking systems.¹⁰¹

4. Technology and social care after the Covid-19 pandemic

In addition to the overall trends in the use of new and emerging technologies in social care, the Covid-19 pandemic may have changed, expanded, or deepened the development and use of technology in the field of social care in four key areas:

Remote connection: videoconferencing seems destined to play a greater role, as an aid to maintaining contact with family and friends, but also as a vehicle for service delivery, medical appointments and assessments, leisure and recreation, and homeworking.

Data collection and integration: the pandemic revealed the analogue nature of much record keeping in social care and has acted as a spur to digitalise social care, and in particular to digitalise social care records, integrated with health and social welfare records.

Self-care assistants, remote support and robots: the challenges of human care-giving while maintaining strict infection control measure could lead to an acceleration in innovation with respect to ‘non-human’ care-giving,

100 Sarah Marsh, ‘One in three councils using algorithms to make welfare decisions’, *The Guardian* (15 October 2019), <https://www.theguardian.com/society/2019/oct/15/councils-using-algorithms-make-welfare-decisions-benefits>

101 Lydia Nicholas and Catherine Miller, ‘Better Care In The Age Of Automation’, Doteveryone (2019) at 14, https://doteveryone.org.uk/wp-content/uploads/2019/09/Doteveryone_Better-Care-in-the-Age-of-Automation-1.pdf



such as through robotics and in technologies that support older people and informal care-givers to ‘self-care’ including medical chatbots, smart housing and remote monitoring and support.

Online ‘marketplaces’ of social care: though not strictly a product of the pandemic there appears to have been a growth in online ‘marketplaces’ through which people can find and buy paid care, directly from self-employed care-workers or via online care agencies.

Despite these current and anticipated developments, legal, regulatory, and decision-making frameworks appear aligned to a more analogue age. As noted in the introduction, while there is now greater attention to the regulation and governance of new and emerging technologies, their use in social care largely remains absent from policy debates, even though many technologies are already being used or developed with serious implications for whether it enhances or denies older people’s human rights and whether it advances a rights-based approach to social care or diverts care back to the medicalised model. We discuss the human rights implications of these technologies in the next section of this report.



III. TOOLS TO ADVANCE OR PUT AT RISK THE HUMAN RIGHTS OF OLDER PERSONS?

As noted at the outset, whether new and emerging technologies provide older people with greater autonomy, dignity, and independence or inhibit choice and control turns on a range of factors. In this part of the report, we discuss how these factors can shape the enjoyment or denial of human rights. We identify the need to overcome digital divides as a precondition to technologies contributing to a rights-based model of social care for older people. We also ask whether these technologies will enhance or restrict privacy and dignity; increase or decrease social inclusion; return older people to the traditional model of substitute decision-making or facilitate autonomy and self-determination through supported decision-making; secure or deny the rights to liberty and freedom of movement; and provide greater freedom from violence and exploitation or provide a new vehicle for it. We do so to show how the way in which technologies are used and implemented can either accelerate or adversely affect the enjoyment of human rights.

We observe that perceptions and preferences matter, meaning that any analysis must navigate objective and subjective accounts of the implications of new and emerging technologies for human rights. For example, while some express fears that technology will displace human contact, which is deemed fundamental to good care and support, others see technology as enhancing human caregiving, for example by freeing people from practical tasks such as preparing food and assisting with personal care, in order to focus on the social and relational aspects of care and support.¹⁰² Some regard technology as offering a route to independence from relatives or paid care-workers, or as a way to transform the nature of those relationships. As Shirley Ayers explains,

I want a smart affordable small home, a social robot and access to driverless electric cars to take me to see my family and friends so that I can be truly independent. I want to live in a multi generational community with space for residents to connect and pursue shared interests and leisure pursuits. I want an affordable eco friendly home which is so well designed my grandson would want to live there too. All

102 Tom Sorell and Heather Draper, 'Robot Carers, Ethics, and Older People', 16 *Ethics and Information Technology* 183 (2014), at 185.

<https://link.springer.com/article/10.1007/s10676-014-9344-7>; Karolina Socha-Dietrich, 'Empowering the Health Workforce: Strategies to Make the Most of the Digital Revolution',

OECD (2020) at 26, <http://www.oecd.org/health/health-systems/Empowering-Health-Workforce-Digital-Revolution.pdf>



.....

this is possible with developments in technology, artificial intelligence and new building methods. It requires vision, imagination and changing the mindset of an industry which still spends billions of pounds on residential care. We need to listen to, and work with, the increasing number of people who have no interest, desire or aspiration to end their lives living in an institution rather than their own home.¹⁰³

Technologies that objectively expose people to greater risks to privacy, by drawing upon intimate personal data either to achieve their functionality, or as the price of using them, can nevertheless be subjectively experienced by people as providing greater privacy, by minimising direct human observation in the intimate areas of daily life. Technologies which constantly monitor and share a person's physiological or mental wellbeing, or their location, under the rubric of safeguarding, may help avoid people being deprived of their liberty, or from being obliged to accept a particular living arrangement, yet invite an unprecedented degree of intrusion into their innermost lives, even if they do not immediately perceive it as such as the technology removes the need for direct human observation.

Further, the human rights implications of new and emerging technologies are not wholly intrinsic to the technologies themselves but are shaped by their social, political and economic context. In this regard, of equal importance are:

- The motivations lying behind their use or application;
- The context in which they are used;
- The purpose to which they are put;
- How people and organisations interact with them;
- How the technologies interact with each other now and in the future;
- The ethical, legal and regulatory frameworks governing their use and application;
- The wider model of social care, as discussed above.

This is as true of new and emerging technologies in the context of social care as it is all spheres of life. The pace of change and the uncertainties this creates makes prediction of risks and opportunities challenging. In

¹⁰³ See: Community care and care homes <https://keyahconsulting.com/responding-to-covid-19-community-care-and-care-homes-webinar-2/>



the following analysis, we reflect upon the opportunities and risks, both current and foreseeable, that effective policy, regulation, and other action should strive to harness, constrain, or eliminate.

A. Progressive realisation or cost containment?

As we noted at the outset of this report, the introduction of new and emerging technologies in the field of care could help to advance a rights-based approach to social care for older people, or it could simply embody policy and practice oriented towards cost containment and which frames care as ‘maintenance’.

Measures to optimise efficiency and productivity are not intrinsically at odds with states’ obligations under international human rights law to take steps to progressively realise economic, social, and cultural rights to the ‘maximum of their available resources’.¹⁰⁴ By enabling scarce resources to go further or to be used more effectively, new and emerging technologies could help accelerate such progress. However, in her report to the Human Rights Council, the UN Independent Expert on the enjoyment of all human rights by older persons asserted that, ‘[t]he introduction of technology cannot substitute for the State’s obligations to support older persons. It should also not lead to a collective disengagement from the duty to support them’.¹⁰⁵

It is notable then that the case made for the development and adoption of new and emerging technologies in the context of care and support is often to achieve savings or to contain costs. For example, the UK think tank, the Institute for Public Policy Research, has calculated that 30% of work done by adult social care staff could be automated ‘by adapting currently demonstrated technology’ (technology already available), with savings and improvements valued at £6 billion.¹⁰⁶ However, the costs of such automation in terms of the nature and quality of care and support can often seem a secondary consideration. In its report, *Better care in the age of automation*, DotEveryone draws attention to the risk that the ‘widgetisation’ of care delivery on the nature and quality of care and support where cost-saving rather than improving the quality of care is the priority:

¹⁰⁴ UN Committee on Economic, Social and Cultural Rights ‘General Comment No 3: The Nature of States Parties Obligations (Art. 2, para. 1, of the Covenant) E/1991/23 (14 December 2019)

¹⁰⁵ ‘Report of the Independent Expert on the enjoyment of all human rights by older persons’ (n8), at §44.

¹⁰⁶ Lord Darzi, ‘Better Health and Care for All - A 10-point Plan for the 2020s’; Institute for Public Policy Research (June 2018), p 27, <https://www.ippr.org/files/2018-06/better-health-and-care-for-all-june2018.pdf>.



[c]urrently care providers are incentivised to use technology to cut staff ... This has led many providers to invest in technologies that get their staff to hit critical targets in as little time as possible, with increasingly detailed and regimented scheduling platforms and tracking systems ... done badly, they give no space for carers to respond with compassion and creativity to the unique challenges of each care appointment.¹⁰⁷

As noted above, it also appears that a significant proportion of the new and emerging technologies that are used in the context of care for older people are procured privately by individuals or families, for example to monitor, remind, or stay in touch with relatives when families cannot physically be present. Though it is beyond the scope of this report to provide definitive evidence, it would seem intuitive that, notwithstanding the benefits that such technologies can offer, they are increasingly occupying a space vacated (or not yet filled) by state-funded social care on the one hand, and the diminishing capacities of families to provide unpaid care on the other.

B. Tech for everyone, or widening ‘digital divides’?

In the research for this report, an interviewee pointed to the ongoing digital exclusion of older people as having major implications for the human rights of those drawing upon care and support.¹⁰⁸ The UN Secretary General has noted that half the world remains offline, with older people ‘disproportionately offline’.¹⁰⁹ In the UK, the Office for National Statistics reported that in ‘2018 there were still 5.3 million adults in the UK, or 10.0%’ of the population who are what it terms ‘internet non-users’, defined as people who have ‘either never used the internet or have not used it in the last three months’.¹¹⁰ It found that, ‘adults over the age of 65 years have consistently made up the largest proportion of the adult internet non-users’; disabled adults make ‘up a large proportion of adult internet non-users’; ‘wide disparities [exist] between ethnic groups’ and ‘[a]mong those of working age, the economically inactive are the most likely to be internet non-users, particularly those adults

¹⁰⁷ Nicholas and Miller (n100), at 14.

¹⁰⁸ Interview 2 (14 October 2019).

¹⁰⁹ UN Secretary-General, ‘Policy Brief: The Impact of COVID-19 on Older People’ (May 2020), 10, <https://www.un.org/development/desa/ageing/wp-content/uploads/sites/24/2020/05/COVID-Older-persons.pdf>.

¹¹⁰ Office for National Statistics, ‘Exploring the UK’s Digital Divide’ (4 March 2019), <https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/articles/exploringtheuksdigitaldivide/2019-03-04>.



on long-term sick leave or disabled'.¹¹¹ In 2018, a study by the UK Centre for Ageing Better reported that people over 55 make up 94 per cent of non-users of the internet, with 4.5 million people over the age of 55 who are not online.¹¹² The report states that they are a group likely to be poorer, less healthy and less well educated than their peers.¹¹³ Further divides arise from the accessibility and useability of the technology.¹¹⁴ These include where digital divides stem from the inaccessibility of technology for people with visual, aural or cognitive impairments for example, rendering devices unusable by parts of the population.

Given the increasing digitisation across all areas of life, including shopping, banking, access to public services, wayfinding and communication, there is clearly enormous potential for new and emerging technologies to reinforce and deepen existing patterns of inequality in terms of people's opportunities to harness technology to secure their own wellbeing and to actively participate in society. Further, those who have the greatest reliance upon state-funded or arranged support may increasingly find themselves subject to higher levels of surveillance, intrusion, loss of privacy, and control over personal data.

Divides in access to physical devices may widen further between those who cannot afford internet-enabled smart devices and other forms of AI-enabled devices, unless they are provided as part of social care packages by the state. Equally, new types of structural inequalities may emerge. For example, where people have to pay for their own social care, it is conceivable that some will opt for AI-enabled devices to 'deliver' some forms of care instead of human-delivered care due to limited resources, although as noted above, while much is often made of AI-enabled technologies, they are not yet at the stage of technological development where they could substitute for human-delivered care. There are further risks that some people may be able to access internet and AI-enabled devices at low or no cost but based on restrictive terms and conditions that allow their data to be collected, stored, analysed, and sold in ways that adversely affect their privacy and wider human rights.

111 Ibid.

112 Centre for Ageing Better, 'The Digital Age: New Approaches to Supporting People in Later Life get Online' (May 2018), 1, <https://www.ageing-better.org.uk/publications/digital-age>.

113 Ibid.

114 Neil Crowther and Lisa Waddington Digitalisation and digital transformation in Europe: Implications for the rights of persons with disabilities Synthesis report European Disability Expertise (2022 forthcoming).



As technology becomes more sophisticated but opaque, existing data literacy is likely to be aggravated further, creating wider digital and AI divides, and putting older people with low data literacy at risk of 'consenting' to data collection and use in ways that they may not understand or be able to opt out of. As discussed further below, exercising meaningful consent to the use of new and emerging technologies is the subject of significant critique and in the field of social care presents further risks that decisions are made on behalf of a person where issues of capacity are raised.

As noted above, a lack of personal engagement with the internet or internet-enabled devices does not mean that people's lives are not touched by technology. However, their direct absence from the internet as producers of content, consumers, and participants is likely to be mirrored in either their invisibility or misrepresentation on the internet, or in the design and development of data-driven technologies.

C. Privacy enhancing or putting privacy at risk?

The use of technology in social care presents risks to people's privacy. For example, the employment of technologies in people's homes poses risks to health data, personal and private information, including people's innermost thoughts and opinions which they may not voice or express outside the home. The risks to privacy not only apply to the older person but also to anyone visiting and interacting with them, including through technology. As privacy is a gatekeeper right, where the data generated by the use of new and emerging technologies is accessed, analysed, shared, or sold to other actors, many other human rights may be put at risk.

The extent of the invasion into a person's privacy will depend on the nature of the technology; how data is collected, stored, analysed, and shared; who has access to it; and the extent to which the user is aware and able to control privacy settings and data flows. These issues are rarely made clear to users. Examples of how data can be generated from new and emerging technologies in social care, include:

- **Health-related AI:** voice-based virtual assistants - using speech recognition and natural language processing - continuously monitor patients and generate health data, including biometrics, observable behaviours, and medications taken.
- **Monitoring devices:** the type of technology used will have an impact on a person's privacy, with cameras and facial recognition technologies at the extreme end. Other technologies may be less



visually intrusive, such as lasers, as they do not capture images of the person and may not be AI-enabled. While these types of technologies may be less intrusive in terms of the images captured, they still raise privacy issues where they can generate and analyse a range of health and behavioural data about a person.

Other technologies are designed to learn a person's daily routines. For example, any significant anomaly in behaviour or deviations from routine activity patterns can be automatically reported to nurses or caregivers as a potential health or safety issue.

Part of the appeal of some of these technologies is that they may appear to provide greater privacy to older people than a human care worker. For example, monitoring devices whether camera, laser or 'acoustic listening' involve continuous monitoring of sound levels in a room throughout the night, alerting care staff to any unusual sounds that might indicate a person is out of bed or has fallen. These may be used within a person's bedroom in place of routine physical checks by care staff and therefore seem like they provide more privacy. However, such technologies may only create the illusion of privacy, or leave people with a stronger subjective sense of privacy, while objectively exposing their private lives and personal data to a wider range of observers. Thus, it is important to underscore that while the use of technology in this way could provide more physical privacy from humans in the same place as the older person, it may expose them to intrusions into their privacy in other ways depending on how the technology is designed and implemented and who is able to access and interpret the data (potentially including images) of the monitoring device.

These technologies can enable families and others to monitor the health condition of older people and the data generated by these technologies may be used by older people, families, care providers and/or clinicians as a support tool to prevent or proactively address risk in real time. However, significant risks can arise from the interpretation of the data, particularly if assumptions are made about specific behaviours and what they indicate about a person's physical or mental health. These risks not only relate to the right to privacy itself, but also any further action taken as a result of analysis of the data, which at its most extreme could entail



coercive treatment, restrictions to freedom of movement, or deprivation of liberty as discussed further below.¹¹⁵

Accordingly, how data from such devices is captured, generated, stored, and accessed may have significant implications for a person's privacy and their wider human rights. An issue that is particularly unclear is the extent to which particular technologies need to collect data in order to function or whether data is collected as it is commercially advantageous. For example, Cunneen et al note how artificial intelligence assistants (AIAs) are 'marketed and labelled as an assistant, but the core design and functionality comprise user data analytics for downstream commodification. Such duality underscores the commercial dependency on data harvesting and analytics and raises questions as to the volume of specific data actually required to support functionality'.¹¹⁶ Understanding whether the collection of data is necessary for functionality or to increase profit is important as it highlights that data minimizing solutions may be available, such as storing data locally on devices rather than on centralized servers, in order to limit access.

Consent is often presented as a way to protect privacy. While the EU General Data Protection Regulation ostensibly protects users in such situations,¹¹⁷ in practice, consent processes can be unclear and cumbersome and thus result in people formally consenting to particular forms of data extraction and use without a meaningful understanding of the risks and potential uses.¹¹⁸ The explanations of how data will be used (in the short or long-term) are often not comprehensive or clear enough. Critiques of consent as a protective measure highlight that the onus is typically placed on users to protect their privacy through consent, without providing the possibility of exercising meaningful consent or influencing the way in which the product is used.¹¹⁹ For example, access to a product may be conditioned on an overly broad form of consent with little possibility of shaping the terms and conditions.¹²⁰

¹¹⁵ Gooding et al (n8).

¹¹⁶ Martin Cunneen, Martin Mullins and Finbarr Murphy, 'Artificial Intelligence Assistants and Risk: Framing A Connectivity Risk Narrative', *AI & Society* 625 (2020), at 630.

¹¹⁷ European Parliament and Council Regulation 2016/679/EU of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC [2016] OJ L119/1 ('GDPR'), art 7 and art 9.

¹¹⁸ Human Rights, Big Data and Technology Project, 'Background Paper on Consent Online' (December 2019), 2.

¹¹⁹ Cunneen et al (n115), at 629.

¹²⁰ Ibid.



If the technology is installed by the state or an independent private provider, for example, in a care home or residential setting, there is also the risk that the individual user is not able to exercise consent, but rather the terms are set by the provider and the individual user is then left in a 'take it or leave it' position. There is also a risk that the older person has no opportunity to access the data sharing agreement between the technology provider and the state or private provider, to shape or personalise it. This is a particularly important point as a person's privacy is acutely at risk where data sharing agreements or the terms and conditions of the specific technology allow for the collection, triangulation with data collected from other devices in the home or other data about the person, analysis, storage, sharing or sale of the data to other actors. Questions therefore arise about the transparency entailed in the data governance of new and emerging technologies and the purposes and use cases for data extraction and the extent to which older people are able to control how their data is collected, stored, analysed and shared. As noted at the outset, in the absence of meaningful consent about the role of new and emerging technologies in older people's lives, the risk that their need for care and support is instrumentalised by the actors designing, developing, and deploying these technologies becomes acute. This risk is heightened even further where the business model of some tech providers and data brokers centres on the extraction, analysis, and sale of data.

For example, the introduction of monitoring technologies may provide local authorities and independent private care providers with much greater data and insight into a person's life than would be possible – or permissible – from a human caregiver, particularly if that person only visits a few times a day. This data could be highly valuable to governments and private actors but as discussed above may violate a person's privacy and have wider consequences for their life. For example, local authorities or health services could use these data to make decisions about resource allocation and access to services. While this could be beneficial and ensure that those who need support the most receive it, it could also result in people being denied treatment. If the providers of the technology are able to use the data or share or sell it to private companies, these third parties could profile and target older people with products or services. It could also impact decisions on access to, and the rate of, insurance.¹²¹ Access Now argues that,

[i]nsurance actors have for some time perceived digital forensics as an economical means of constructing more informed risk assessments regarding social behaviour and lifestyles. This type of

¹²¹ For example, *ibid* at 627.



granular data on driving skills sets and perhaps on attitudinal traits around the driving task (derived from AI assisted driving technology) could allow the insurers to more accurately metricise risk. For an individual, the consequences are fairly obvious in rising premium costs or even in some cases no access to insurance. However, for society the long-term impacts may be less apparent in that it may result in cohorts of people being deemed uninsurable and therefore denied access to the roads.¹²²

Further challenges may arise where a determination that the older person lacks ‘legal capacity’ results in someone else consenting on their behalf. Substitute decision-making does not comply with the UN CRPD,¹²³ which underscores the need for supported decision-making to enable a person to make decisions about their own lives rather than someone else deeming what is in their ‘best interests’. It is particularly important where new and emerging technologies are used as part of social care as without the input of the person concerned, decisions over whether and which forms of technology to employ may be made by family members or caregivers, who may prefer more intrusive forms of technology to monitor for falls or track a person’s movements from a safety perspective, even if it conflicts with the person’s will and preferences. The challenges around consent and substitute and supported decision-making are discussed further below.

The significant risks to older people’s privacy, and the privacy of those interacting with the person, and the serious consequences that can result from the interpretation of such data which are not complete, contextualised, or neutral, underscore the critical importance of developing strong privacy protection frameworks that address which data are collected and accessible in the first place as well as finding new models that place the burden of protecting privacy on the designers and providers of such technology rather than users. This is even more important in the field of social care to ensure that decisions are not made on behalf of a person where they are deemed to ‘lack’ capacity and where complex constraints in their lives mean that they experience cumulative disadvantage in the exercise of their agency. Rather, the focus needs to be on the development of models of supported decision-making in order to respect autonomy and instruments such as advanced planning take into account the possibility of the availability of new and emerging technologies as part of the delivery of social care.

122 Access Now, ‘Human Rights in the Age of Artificial Intelligence’ (2018), 26, <https://www.accessnow.org/cms/assets/uploads/2018/11/AI-and-Human-Rights.pdf>

123 CRPD, Article 12.



D. Free from human bias, or discrimination by algorithm?

The increased use of algorithmic decision-making by both public and private institutions to aid human decision-making has already been a focus of concern due to the potential for bias and discrimination, for example, with respect to its use in jobs recruitment.¹²⁴ As predictive algorithms and machine learning are increasingly used to determine risk and in decision-making about the distribution and allocation of public resources, such as health treatments and publicly-funded care and support, similar issues may emerge. New and emerging technologies may either embody the biases of their human programmers, or the use of machine learning algorithms in decision-making may lead to decisions that fail to accord with the rights of non-discrimination and equality. As the Council of Europe Commissioner for Human Rights has cautioned,

[m]achines function on the basis of what humans tell them. If a system is fed with human biases (conscious or unconscious) the result will inevitably be biased. The lack of diversity and inclusion in the design of AI systems is therefore a key concern: instead of making our decisions more objective, they could reinforce discrimination and prejudices by giving them an appearance of objectivity. There is increasing evidence that women, ethnic minorities, people with disabilities and LGBTI persons particularly suffer from discrimination by biased algorithms.¹²⁵

We can confidently add to this list ageist assumptions and prejudices, and those about people who require or who use social care and support. As the WHO notes:

Although there is substantial evidence that older people contribute to society in many ways, they are instead often stereotyped as frail, out of touch, burdensome or dependent. These ageist attitudes limit the way problems are conceptualized, the questions that are asked, and the capacity to seize innovative opportunities. As a starting point for policy-making, they often lead to great emphasis on cost containment.¹²⁶

¹²⁴ Access Now, 'Human Rights in the Age of Artificial Intelligence' (2018), 26, <https://www.accessnow.org/cms/assets/uploads/2018/11/AI-and-Human-Rights.pdf>

¹²⁵ Dunja Mijatović, Commissioner for Human Rights, 'Safeguarding Human Rights in the Era of Artificial Intelligence', *Council of Europe* July 2018, <https://www.coe.int/en/web/commissioner/-/safeguarding-human-rights-in-the-era-of-artificial-intelligence>

¹²⁶ WHO, 'World Report on Ageing and Health' (n37), at 10.



Conversely, such technologies may be better able to recognise and root out patterns of systemic human bias and discrimination, leading to improved and more human rights-compliant decision-making.¹²⁷ However, our engagement with stakeholders and analysis of available literature strongly suggests that ageism is largely unrecognised, including by some human rights advocates.¹²⁸ This is an important concern both in terms of ensuring that the technology is fit for purpose and in preventing harm due to the failure to take into account the impact on older people.

Social prejudice can also present a barrier to adopting new technologies. DotEveryone found that '[m]any benefits claimants are reluctant to adopt new technologies because they fear any change in their lives could jeopardise vital support packages. Older and disabled people feel excluded from an ableist and ageist design community and complain of unsuitable and unappealing products that don't take into account their own goals, ideas and experiences'.¹²⁹

Without concerted action to address current patterns of digital exclusion faced by older people, there is a serious risk that technology will perpetuate and deepen rather than help to resolve age discrimination and inequality. In such a scenario, many older people, particularly those with the fewest resources, may find themselves the objects of automation, rather than empowered to instrumentalise new and emerging technologies to pursue a life they have reason to value.

E. Supported or substitute decision-making?

As with their development, application, and use more generally, new and emerging technologies are playing an increasing role in matters of comprehension, memory, choice, and decision-making where older and disabled people are concerned, with particular implications for the maintenance of personhood and the exercise of autonomy.

¹²⁷ Philip Hacker, 'Teaching Fairness to Artificial Intelligence: Existing and Novel Strategies Against Algorithmic Discrimination Under EU Law', 55 *Common Market Law Review* 1143 (2018), at 1144.

¹²⁸ Interview 2 (14 October 2019).

¹²⁹ Nicholas and Miller (n100), at 8.



The approach to autonomy and decision-making advanced by the UN Committee on the Rights of Persons with Disabilities adds a further layer of complexity to this discussion. General Comment 1 of the UN Committee on the Rights of Persons with Disabilities concerns the interpretation of Article 12 of the Convention on equal recognition before the law. It notes that, '[t]he denial of legal capacity to persons with disabilities has, in many cases, led to their being deprived of many fundamental rights, including the right to vote, the right to marry and found a family, reproductive rights, parental rights, the right to give consent for intimate relationships and medical treatment, and the right to liberty'.¹³⁰ The Committee notes how states have instituted, 'substitute decision-making regimes' that, 'can be defined as systems where: (i) legal capacity is removed from a person, even if this is in respect of a single decision; (ii) a substitute decision maker can be appointed by someone other than the person concerned, and this can be done against his or her will; or (iii) any decision made by a substitute decision maker is based on what is believed to be in the objective "best interests" of the person concerned, as opposed to being based on the person's own will and preferences'.¹³¹ It calls on states to repeal all such regimes and to replace them with 'supported decision-making regimes' which are characterised as comprising 'various support options which give primacy to a person's will and preferences and respect human rights norms'.¹³² Lucy Series explains that, '[t]his new approach treats a person's agency as shaped or even constituted by their environment and relationships with others. Instead of casting 'mental capacity' as an individual deficit, resulting in a loss of legal capacity, it calls for the provision of whatever support is necessary to ensure that disabled people are able to exercise full legal capacity on an equal basis with others, and addressing discriminatory attitudes and barriers that might limit the recognition and exercise of legal capacity by disabled persons'.¹³³

New and emerging technologies hold the potential to support older people's memory and their capacity to make autonomous decisions. Nevertheless, in common with other forms of technologies, new and emerging technologies that can provide reminders or monitor people taking medication; provide prompts and assist with the organisation of the day; or even be integrated into a smart home have the potential to harm or

¹³⁰ UN Committee on the Rights of Persons with Disabilities (n2), at §8.

¹³¹ Ibid, at §27.

¹³² Ibid, at §29.

¹³³ Lucy Series, 'Relationships, Autonomy and Legal Capacity: Mental Capacity and Support Paradigms', *International Journal of Law and Psychiatry* 80 (2015), at 80.



enhance the enjoyment of human rights, depending on who decides to use them, the purpose of use, and their design and deployment.

These technologies may support people to be safer while living outside of institutional care and enable them to live free from constant human supervision, potentially expanding and enhancing the enjoyment human rights. Nevertheless, the question remains as to whether, when used in these ways, they are supporting people to exercise their will and preferences or removing autonomy from people in the pursuit of other goals deemed to be in their ‘best interests’. This question becomes particularly acute when the machine learning and predictive capabilities of data analytics are also engaged.

Academics and practitioners have expressed concerns about the negative impact of algorithmic processes on ‘cognitive autonomy’. For example, Mireille Hildebrandt observes that, ‘we are learning slowly but steadily to foresee that we are being foreseen, accepting that things know our moods, our purchasing habits, our mobility patterns, our political and sexual preferences and our sweet spots. We are on the verge of shifting from *using technologies* to *interacting with them*, negotiating their defaults, pre-empting their intent while they do the same to us’.¹³⁴ Concern that such technological capacities may limit human agency and autonomy lie behind statements by the Parliamentary Assembly of the Council of Europe on ‘manipulative capabilities of algorithmic processes’.¹³⁵ It expresses concern that, ‘[f]ine grained, sub-conscious and personalised levels of algorithmic persuasion may have significant effects on the cognitive autonomy of individuals and their right to form opinions and take independent decisions ... Not only may they weaken the exercise and enjoyment of individual human rights, but they may lead to the corrosion of the very foundation of the Council of Europe. Its central pillars of human rights, democracy and the rule of law are grounded on the fundamental belief in the equality and dignity of all humans *as independent moral agents*’.¹³⁶

Many new and emerging technologies in the field of care are explicitly designed to influence people’s choices and behaviours to achieve particular results, such as supporting a person to adhere to a course of medication,

134 Mireille Hildebrandt, *Smart Technologies and the End(s) of Law: Novel Entanglements of Law and Technology* (2015) at ix.

135 Council of Europe, ‘Declaration by the Committee of Ministers on the manipulative capabilities of algorithmic processes’ (13 February 2019), at §9,

https://search.coe.int/cm/pages/result_details.aspx?ObjectId=090000168092dd4b.

136 *Ibid* (emphasis included in original).



or to support a person to live independently in the community but without human support. Where a technological application has been selected and programmed with the consent and involvement of those interacting with it, then it may be characterised as ‘supported decision-making’, upholding the will and preferences of the person. However, there may also be instances where either the technology is programmed by third parties, such as local government, a care provider, or a family member, without the consent or involvement of the person interacting with it, amounting to ‘substitute decision-making’, potentially in conflict with a person’s will and preferences, even if deemed to be in a person’s ‘best interests’.

A further dimension is introduced where new and emerging technologies include the capacity to make predictions, to support decision-making about the person or are used as a tool to influence or restrict their choices and behaviours in relation to issues such as health and safety risks, whether they leave their home or how far from home they can travel. On the one hand, where the person has given free and informed consent to the use of such technology to achieve results they consider important, then it may again be regarded as a mode of supported decision-making. However, neither the individual nor the designers of the technology can know with certainty what strategies the technological application might employ to achieve its set goals and hence the durability of any consent should it begin to adopt methods that fail to accord with the persons will and preferences, or which involve coercion, for example. Moreover, there is risk that some designer and manufacturers, as well as commissioners, overplay the potential – even if the technological capability to carry out specific functions is not yet proven - while underplaying the risks of certain predictive or AI-enabled technologies, causing them to be relied upon beyond that which is possible, safe or sustainable.

Some commentators have expressed concern that technologies that impact cognitive autonomy may not only rob humans of the functional ability to exercise autonomy and agency, but may also diminish our intrinsic cognitive capacities to do so. For example, because humans increasingly rely upon technology for recall, writing, or for finding one’s way around, concerns arise that we become dependent on technology to the extent that we will fail to develop, or experience decline in, the cognitive capacities that are instrumental to



such functioning.¹³⁷ However, these concerns must be balanced against evidence of the potential cognitive benefits of using digital technologies in later life than can strengthen intrinsic capacities.¹³⁸

It is unclear what consideration is given to the impact on intrinsic capacities of introducing particular forms of technology into the context of care for older people. It could be conceivable that the very same predictive capacities of algorithmic processes that have been characterised as a threat to human rights could also play a valuable role in assisting the transition from ‘substitute’ to ‘supported decision-making’. Specifically, if certain forms of new and emerging technologies are developed which become so sophisticated as to ‘know us’ deeply and to pre-empt our behaviour or intent, then they may be capable of helping to reaffirm our identity, will and preferences when we, as a result of dementia for example, struggle to express or act upon it ourselves. Our extensive ‘digital footprint’ could act as a future guarantor of our human rights as part of a framework of ‘supported decision-making’ that helps protect and promote respect for identity, will and preferences, alongside other mechanisms such as representation agreements or advance directives for example.¹³⁹

Nevertheless, questions will likely remain about whether algorithmically aided decision-making amounts to substitute or supported decision-making. For example, how could we be certain that a technological application represents a person’s authentic will and preferences rather than an inaccurate or biased interpretation of what it believes them to be? How could it avoid resulting in the same problems as with substitute decision-making, deciding what it believes to be in a person’s best interests, shaped by the will and preference of those who designed an algorithm? How can we be confident that through interaction, the technology does not unduly influence a person’s choices and decisions, or embodies biases as a result of its original training data having been influenced by the biases of its programmers? Further, as Quentin André et al note, ‘...automated curation based on past preferences would make a given individual’s opinions and

137BBC Radio 4, ‘What has Sat-Nav Done to our Brains?’ (17 December 2019), <https://www.bbc.co.uk/sounds/play/m000c9rm>.

138 See for example, Gary et al ‘Brain Health Consequences of Digital Technology Use’ *Dialogues in Clinical Neuroscience* 179 (June 2020) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7366948/>

139 See for example Series (n132).



preferences more stable over time than they would normally be. Contrary to what common wisdom suggests, individuals' personality and tastes continue to change significantly through adulthood'.¹⁴⁰

In this regard, how could we be certain that the technology was representing a person's current, rather than past, will and preferences (a question of particular relevance in the context of life and death decision-making)? This point is accentuated since technology would only be drawing on digitised data, which would therefore not provide a complete picture (and possibly only a fraction despite claims that are often made that our digital devices know more about us than those closest to us) of a person's thoughts and preferences. The data available may also be inaccurate in that a person may consciously or sub-consciously adjust their behaviour because of concerns about interaction with technology and the actors that may have access to it. Or, alternatively, they may assume different behaviours, and how they choose to express their identity, will and preferences offline and not wish for their 'digital footprint' to inform how others perceive, treat or engage with them in the offline world. Finally, real risks would remain of others harnessing the technology to exercise control over others, to abuse or to exploit them.

In conclusion, new and emerging technologies present both opportunities and threats with respect to supporting older persons to exercise their right to autonomy. Conclusions drawn may change dependent upon how autonomy is understood and defined. To those ends, we conclude that there would be real advantage in a deeper exploration of the issues raised in this section. In particular, we consider that there would be considerable mutual benefits to be derived from a dialogue between those concerned with the rights to autonomy in relation to disability and ageing and those focused on the impact on autonomy of emerging technology generally.

F. Liberty or confinement?

A number of UN treaty bodies, including the Human Rights Committee and the Committee Against Torture, have issued recommendations to states to adopt less restrictive practices than the detention and coercive treatment of people with mental health problems or intellectual disabilities, including reducing or eliminating

¹⁴⁰ Quentin André, Ziv Carmon, Klaus Wertenbroch, Alia Crum, Douglas Frank, William Goldstein, Joel Huber, Leaf van Boven, Bernd Weber, Haiyang Yang, 'Consumer Choice And Autonomy In The Age Of Artificial Intelligence And Big Data', *Consumer Needs and Solutions* 2018, 28-37, 34, <https://link.springer.com/article/10.1007/s40547-017-0085-8>.



reliance on institutional care and minimising or eliminating the use of physical and chemical restraints.¹⁴¹ Technology may have a positive role to play in facilitating this shift in policy and practice. For example, the UN Independent Expert on the enjoyment of all human rights by older people has noted how:

[s]etting boundaries for people with cognitive impairments to roam safely is, for instance, part of dementia care. Electronic bracelets and GPS systems are used as a substitute for locked doors or chemical sedation ... Alternatives to deprivation of liberty and restraints for older people suffering from dementia may include multi-sensory environments, augmented reality and support escorts.¹⁴²

The UN Committee on the Rights of Persons with Disabilities characterises any detention or deprivation of liberty on grounds of disability as discriminatory and not in compliance with the UN CRPD.¹⁴³ Hence, technology that facilitates less restrictive practices without eliminating them may be judged to be part of an approach that is in violation of the human rights of persons with disabilities and could also be interpreted to be a net-widening measure rather than one that supports the eradication of deprivation of liberty. That is to say, technology may act as a boundary to people's lives in the same way as the physical walls of an institution, rather than to liberate them, marking only the modernisation of institutional practices, not their abandonment.

For example, technology might facilitate the de facto deprivation of liberty of people with mental health problems in their own homes by tracking and controlling their movement, their ability to leave their home freely or by policing medication regimes. Deprivation of liberty has typically been understood to refer to situations in which a person does not consent to their placement in a hospital, institution or care homes and is unable to leave.¹⁴⁴ However, case law in the United Kingdom now includes community settings, where a person is deemed to lack legal capacity and is under constant supervision and control and not free to leave of

141 UN Human Rights Committee, 'Concluding observations on the fourth periodic report of Paraguay' CCPR/C/PRY/CO/4 (20 August 2019), at §31; UN Committee Against Torture, 'Concluding observations on the second periodic report of Ireland' CAT/C/IRL/CO/2 (31 August 2017) §35-36; UN Committee on the Rights of Persons with Disabilities, 'Concluding observations on the initial report of Kuwait' CRPD/C/KWT/CO/1 (18 October 2019), §29.

142 'Report of the Independent Expert on the enjoyment of all human rights by older persons' (n8), at §65, 67.

143 UN Committee on the Rights of Persons with Disabilities, 'Statement on Article 14 of the Convention on the Rights of Persons with Disabilities' (September 2014).

144 See, for example, ECtHR, *Storck v Germany*, Application No. 61603/00 (16 June 2005); ECtHR (GC), *Stanev v. Bulgaria* (GC), Application No. 36760/06, (17 January 2012),



their own accord.¹⁴⁵ The Former UK Supreme Court Justice, Lady Hale, summed up this position in *Cheshire West* by stating that, ‘a gilded cage is still a cage’.¹⁴⁶ Technology that constantly monitors a person’s location and activity and which limits what they are able to do or where they are able to go (for example, by automatically locking a person’s front door preventing them from leaving home) could be found to constitute a deprivation of liberty. Technology may provide new ways to deprive people of their liberty through constant surveillance.¹⁴⁷

Where technology is limited to performing the role of continuous supervision, it may offer a less intrusive or restrictive method than continuous human supervision. However, it may still be part of an overall approach that amounts to deprivation of liberty where it is designed to inform decisions or action involving limitations on the person’s movements or the use of restraints even where it does not impose them directly. These questions are not exclusive to matters of technology and reflect wider tensions between conceptions of liberty and the care and support that some people may require to live in the community. However, it is important that these questions are explored with respect to the development, procurement, or application of new and emerging technologies that are posited as supporting people to live more freely outside of institutional care.

In conclusion, new and emerging technologies may present opportunities to minimise restrictive practices that have characterised the violation of the human rights of older people in the past, even in the name of safeguarding. However, it is crucial that these genuinely deliver fewer restrictions on liberty, rather than amounting to – or holding the potential to amount to – new and potentially more expansive ways of depriving people of their liberty in the future.

G. Living independently or summoned by algorithms?

The UN Committee on the Rights of Persons with Disabilities has advised that the right to live independently and to be included in the community includes not only choosing where to live and who provides care and

145 P v. Cheshire West and Chester Council and another, P and Q v Surrey County Council [2014] UKSC 19.

146 Ibid, at §46 (Lady Hale).

147 Human Rights Council, ‘Report of The Working Group on Arbitrary Detention’ A/HRC/22/44 (24 December 2012), at §59.



support but also ‘all aspects of a person’s living arrangements: the daily schedule and routine as well as the way of life and lifestyle of a person, covering the private and public spheres, every day and in the long term’.¹⁴⁸

To these ends, the UN Independent Expert on the enjoyment of all human rights by older people has suggested that, ‘[s]elf-learning technology may be a powerful tool to personalise services for older people. Systems could learn the users’ routine and automatically adapt to their preferences... Self-learning technology would need to be programmed in a manner that allows older people to retain control as preferences change and to be able to adapt to unexpected changes’.¹⁴⁹ Similarly, Axel Leblois, President and Executive Director of Global Initiative for Inclusive ICT, suggests that new and emerging technologies will enable devices and operating systems to automatically adjust to the behaviour or particular requirements of the user with particular advantages for older people who are experiencing physical and sensory disabilities, as well as cognitive issues.¹⁵⁰ Data analytics and AI-enabled technologies could also further increase the power of people to access, purchase and craft their own care and support, in line with their will and preferences.¹⁵¹

The exercise of choice and control rests upon the availability of rights-compliant options from which to select. New and emerging technologies may lead to an exponential increase in such options, in particular by helping to decouple choice of living arrangements from access to support; by giving older and disabled people greater control over their own support; by enabling support providers to achieve greater economies of scale; and by reconciling the management of risk with the promotion of independence. The combination of ‘smart’ technologies within the domestic sphere, particularly through smart homes, offers opportunities to enable greater independence of older people and persons with disabilities.

However, the risk cannot be ruled out that new and emerging technologies applied in a domestic setting may replicate the features of institutionalisation outlined in General Comment 5 of the UN Committee on the Rights of Persons with Disabilities on independent living.¹⁵² This could happen if the new and emerging technologies

148 UN Committee on the Rights of Persons with Disabilities, (n4), at §24.

149 ‘Report of the Independent Expert on the enjoyment of all human rights by older persons’ (n8), at §36.

150 Carine Marzin, Plug and Pray? A disability perspective on artificial intelligence, automated decision-making and emerging technologies, European Disability Forum (2018) at 13.

151 For example, The Tribe Project, <https://tribeproject.org/>

152 UN Committee on the Rights of Persons with Disabilities, (n4).



impose regimes and routines to achieve its programmed goals. For example, smart housing using a combination of technologies may offer greater opportunity for people requiring care and support to live in their own homes, reducing the need for human support and facilitating more control over day-to-day life. However, depending on who decides to introduce the technology and their reasons for doing so, it could reduce the level of human support, for example, for efficiency and cost-reduction without necessarily increasing the control and autonomy older people have over their lives. In theory, technology could get to a point whereby its use through smart housing could remove choice and control, subjecting people to regimes about when to get up or go to bed, when to eat, to watch TV, who is able to visit, and whether and when people can leave their home.

Depending on the nature and scale of technological development, future iterations of technology could deepen these risks. For example, AI-enabled technologies could be used to flag non-cooperative behaviour and then take a series of pre-programmed steps based on such identification. Greater independence from human intervention should not be confused with greater individual agency where technology is programmed by humans to require a person to conform to programmed behavioural regimes, or employ coercive or punitive methods to achieve them. At one extreme, this could amount to deprivation of liberty, as discussed above. Moreover, it could undermine the right to choose and control which includes the right to take risks and to make bad decisions, with sub-optimal outcomes. This is a potential problem inherent to the use of AI-enabled technologies that is recognised in other fields. For example, Quentin André et al suggest that ‘the welfare enhancing benefits of technologies (such as smart cars or home automation solutions) can backfire and generate consumer resistance if they undermine the sense of autonomy that consumers seek in their decision-making’.¹⁵³ The desire to be in control – and the risks that come with that - may trump the desire to achieve the optimum outcomes, and instituting technology that removes control, even under the rubric of promoting independence, safety and wellbeing, may in fact undermine wellbeing.

One interviewee also expressed concern that emerging technologies offer opportunities for government to exert greater surveillance and control over the way individuals use public funds to organise their own care and support.¹⁵⁴ For example, Inclusion London has argued that some local authorities have required direct

¹⁵³ André et al (n139), at 29.

¹⁵⁴ Interview 1 (14 October 2019).



payments to be distributed via ‘pre-payment cards’ rather than cash payments, which allow the authorities to track how people are spending direct payments in real time.¹⁵⁵ In this sense, technology might restrict – or have a chilling effect - on the confident exercise of choice and control. Finally, the risk arises that individuals find themselves coerced into accepting technology-based housing and support in the absence of other choices should technology play an increasing role in efforts by states to transition from institutional care to independent living or ‘ageing in place’.

In conclusion, where older people are in a position to choose to harness new and emerging technologies to fashion their own living and support arrangements, the benefits could be considerable. However, where older people are rendered only the objects of technology and automation or instrumentalised by it, even where under the rubric of ‘promoting independence’, some of the most human rights limiting features of institutional care may be replicated.

H. Socially connected or socially isolated?

A common concern that has been expressed about the application of new and emerging technologies in the sphere of care and support is that these technologies risk displacing human contact and relationships and hence deepening the social isolation that characterises some older and disabled people’s lives.¹⁵⁶ Social isolation is a major risk factor for older people, including older people who require or use social care, which can presage declining physical and mental health.¹⁵⁷ Supporting older people to establish or maintain social connections is increasingly seen as a goal of public health policy.¹⁵⁸ Article 19 of the UN CRPD obligates states to develop housing and support options that prevent isolation and segregation from the wider community.¹⁵⁹

¹⁵⁵ In Control, ‘Payment Cards In Adult Social Care – A National Overview’ (2017), https://www.inclusionlondon.org.uk/wp-content/uploads/2018/03/ILSG_PAYMENTCARDS_1017_WEB.pdf

¹⁵⁶ UN Human Rights Council, ‘Report of the Secretary General: Question of the Realization of Economic, Social and Cultural Rights in all Countries: The Role of New Technologies for The Realization of Economic, Social and Cultural Rights’ A/HRC/43/29 (4 March 2020), at §23.

¹⁵⁷ WHO, ‘World Report on Ageing and Health’ (n37), at 11.

¹⁵⁸ Ibid.

¹⁵⁹ CRPD, Article 19.



Connectivity is a word commonly used to characterise the nature and benefits of new and emerging technologies, whether with respect to the role of technologies in enabling connection between people; connectivity between humans and technologies; or connectivity between technologies. There can be little doubt that the internet and the new technologies it has helped give rise to have provided unparalleled opportunities for people to be in touch with one another, irrespective of location and often requiring no more than a lap or desktop, tablet, or smartphone. Families living on opposite sides of the world talk to one another using platforms such as Skype, Facetime and Zoom; people communicate with friends and family throughout the day via applications such as Whatsapp; post updates on platforms such as Facebook and Instagram; and debate current affairs on forums such as Twitter. Like the rest of the population, these technologies support older people to be in touch on an ongoing basis with their friends, families, and communities, and to receive emotional and practical support, at a distance, and have been critical throughout the Covid-19 pandemic.

Technologies are already used, or are under development, that are aimed at acting as a substitute for human interaction or providing additional ways in which to provide support, assistance, and companionship. These are not the multi-purpose care robots sometimes imagined as capable of performing multiple-care tasks such as cleaning, lifting, personal care, and providing companionship. These do not exist commercially or experimentally yet. However, companion, therapeutic and assistive chatbots and robots, as well as robots that can perform limited and specific household tasks such as vacuuming, are increasingly available.

Without commenting on specific models or products, evidence is beginning to emerge of the impact of these technologies on people, including the possibility that some offer therapeutic benefits. However, as with many forms of technology, questions arise as to who makes the decision to use the technology and whether it is aimed at complementing human contact or reducing it. A particular concern in this regard is whether in using companion robots in the context of social isolation, states and private caregivers fail to give adequate attention and resource to effectively addressing social isolation and loneliness in the community through increasing the opportunities for human contact. Others argue that AI-enabled systems should not be used for the purpose of companionship. For example, Margaret Boden has argued that it is inappropriate to utilise AI-enabled systems in the context of inter-personal relationships, given that such systems do not share the human condition and as such, have no ability to empathise. She argues that to suggest otherwise is



deceptive,¹⁶⁰ maintaining that ‘in a human care interaction, it is erroneous to assume that the exchange is primarily utilitarian and functional, but rather that there is an affective dimension and depth of emotional reciprocity which an AI system cannot ever achieve’.¹⁶¹ However, Boden’s assertion rests on the assumption that existing care is inherently relational, rather than transactional. Moreover, her assertion that caregiving demands empathy or inter-personal relationships is not always shared by those requiring support. For example, one interviewee reported that some persons with disabilities expressed preference for technology over human care-workers because it offers the prospect of greater power and control over their support and hence their own lives, and that they can instrumentalise technology to those ends in a fashion that is not possible to achieve with human support.¹⁶²

Whether social care and support is provided by ‘present’ human care workers, or by technology, the issue of social isolation and the importance of social connection persists. Interactions between paid care staff and people drawing on their support or between robots and people drawing on support may ameliorate feelings of isolation and loneliness, but alone they do not help to repair or establish the web of social connections that characterise and sustain full participation in the community.

Some also speculate that rather than displacing human interaction, technology will free people to be ‘more human’, for example by allowing human care workers/givers to focus more time on human interaction, or on supporting participation in the wider community, and less on bureaucracy or manual tasks that current technology can carry out. Conversely, as Doteveryone notes, the ‘widgetisation’ of care could further diminish the scope for ‘relational’ care and support, with tech-administered ‘time and task’ approaches to personal care governing the activities and behaviours of human care workers.¹⁶³ Scottish Care also observes that ‘[t]he failure to build trust and to engage and involve citizens when technology has been introduced into social care settings - whether as a monitoring tool for workers or as a support system for individuals - further risks the

160 Sarah Knapton, ‘Care Bots For The Elderly Are Dangerous Warns Artificial Intelligence Professor’, *The Telegraph* (May 2016),

<https://www.telegraph.co.uk/science/2016/05/30/care-bots-for-the-elderly-are-dangerous-warns-artificial-intelli/>

161 Margaret Boden, ‘The Margaret Boden Lecture – Lecture One’, Varieties of Mind Conference, Cambridge, (13 June 2018), <https://www.youtube.com/watch?v=zNr2BSzqObY>.

162 Interview 3 (15 October 2019).

163 Nicholas and Miller (n100), at 14.



perception that technology is being used as a replacement or substitute for human interaction, rather than as an enabler of even better and deeper human presence and relationship'.¹⁶⁴

In conclusion, the use of technology can create connection and it can isolate people. However, it is important to recognise that, if aligned to human rights standards, both technology or paid human care should be facilitative, offering the means through which people can establish or maintain relationships and connections. The question then, is not whether technology will or should replace human care-workers, but how far either support people to maintain social connection and to avoid isolation and segregation from the wider community.

¹⁶⁴ Macaskill (n7), at 27-28.



IV. CONCLUSION AND RECOMMENDATIONS

As we have underscored throughout this report, the use of new and emerging technologies as tools for meeting people's need for social care and support has the potential to go one of two ways: it could enable older people to live more autonomous but connected, independent, and dignified lives, or it could facilitate the reduction of human-delivered care and interaction, and at the most extreme, replicate some of the worst features of institutionalisation, through control and coercion. Both futures could also co-exist, whereby some older people enjoy the benefits of new and emerging technologies as part of a rights-based model of social care, and others experience them as a means to deny their rights and to further entrench a 'time and task' approach to care with older people 'maintained' by only meeting their basic needs. The following are baseline recommendations for approaching the role of new and emerging technologies in social care. They are not definitive or exhaustive but proposed as a starting point to wider debates and developments in the field:

A. Starting from a Baseline of a Rights-Based Approach to Social Care and to the Governance and Regulation of New and Emerging Technologies

While not determinative, the governance and regulatory environment into which new and emerging technologies are introduced is likely to shape whether new and emerging technologies advance, or obstruct, older people's enjoyment of their human rights. In this regard, the operationalisation of states' existing human rights obligations and companies' human rights responsibilities remains a key priority at two intersecting levels. First, the development, application, and use of technology in the field of social care is already - and will be - shaped by the overall framing and trajectory of care and support itself. In this regard, ensuring that states meet their existing human rights obligations, by adopting a rights-based model to social care, housing and support will increase the prospects of new and emerging technologies advancing, rather than restricting, rights. Second, of equal importance, especially given the widespread consumption and deployment of digital technologies by private citizens to the ends of social care, is the adoption of a human rights-based approach to the design, development, and deployment of new and emerging technologies by states and private actors, including technology companies and care providers, taking into account the diverse and intersectional experiences, goals, and needs of older people. This includes reassessing existing data protection frameworks to ensure that they adequately protect older people from situations in which their access to low-cost or free internet or AI-enabled devices is conditioned on restrictive terms and conditions that allow their data to be



collected, stored, analysed, and sold in ways that adversely affect their privacy and wider human rights, and contributes to structural inequalities. Moreover, where states and private care providers provide AI-enabled devices, the purposes for which they collect, store, analyse, share and sell data may need to be subject to specific regulation.

Within both frameworks, much more attention is needed to understand the extent and nature of current use of new and emerging technologies within social care and the experience of older people, their families, and caregivers of these technologies. This knowledge base and the meaningful participation of older people is important in the shaping of normative and operational principles on the use of new and emerging technologies within a rights-based approach to social care and to prevent intersectional discrimination in the design and development of AI-enabled technologies and services and decision-making processes using such technologies. This would mean avoiding technology being ‘done to’ people and instead assessing the ways in which it can enable older people to people enjoy their rights to live independently, make autonomous decisions and participate in community life as set out in the UN CRPD and to enhance the quality of later life without having to trade-off or give up other rights.¹⁶⁵

B. Overcoming Digital Divides

If older people are to have the option of using new and emerging technologies as tools to advance their human rights, core baseline issues, such as overcoming intersectional digital divides requires urgent attention, including to avoid the realisation of two digital futures, whereby some are able to enjoy the benefits of technology whereas others are excluded or subjected to technology being ‘done to them’.¹⁶⁶ Digital divides continue to exist at multiple levels, such as ongoing barriers to the affordability and accessibility of the internet and new and emerging technologies more broadly, including for older people with visual, aural and cognitive impairments. Moreover, strengthening data and technology literacy is also a critical pre-condition to the exercise of meaningful consent to the use of new and emerging technologies in older people’s lives, as

¹⁶⁵ Council of the European Union, ‘Conclusions on Human Rights, Participation and Well-Being of Older Persons in the Era of Digitalisation’ (9 October 2020), at §27.

¹⁶⁶ WHO, Decade of Healthy Ageing (n3), 67, 126.

discussed below, as well as being able to fully utilise the different functionalities offered by particular technologies.

Developing effective strategies to overcome the digital divides experienced by older people and the inaccessibility of certain technologies constitutes a critical policy objective for states and technology designers and developers. However, it is important that it is not only treated as a contained policy objective within digital strategies but also integrated within wider social care law and policy. For example, overcoming digital divides and the inaccessibility is inextricably linked to initiatives to increase connectivity as part of public health policies.

C. Identifying Red Lines in the Design, Development or Deployment of New and Emerging Technologies for Social Care

Within the wider tech and human rights field, over 15 US cities have introduced bans on the use of facial recognition technologies by law enforcement¹⁶⁷ and civil society organisations have instituted wider campaigns to ‘Ban the Scan’¹⁶⁸ and ‘Reclaim your Face’.¹⁶⁹ The draft EU AI Act also prohibits the use of AI-enabled technologies categorised as ‘unacceptable’. To date, debates and policy initiatives on possible ‘AI red-lines’ have not closely examined whether certain types of technology or use cases in the field of social care should be prohibited. However, given that new and emerging technologies are likely to be used in older people’s homes and for their care and support, this report highlights the critical importance of further analysis of whether AI red-lines should be applied to the use of new and emerging technologies in social care and support.

Clear examples emerging from this report include where new and emerging technologies are used within the community to deprive older people of their liberty or to replicate the control and coercion associated with institutions, even if implemented within their own homes. Article 5(a) of the draft EU AI Act is of relevance to the field of social care in prohibiting, ‘the placing on the market, putting into service or use of an AI system

¹⁶⁷ Nathan Sheard and Adam Schwartz, ‘The Movement to Ban Government Use of Face Recognition’ *Electronic Frontier Foundation* (5 May 2022).

¹⁶⁸ Amnesty International, Ban the Scan Campaign, <https://www.amnesty.org/en/petition/ban-the-scan-petition/>

¹⁶⁹ EDRi, Reclaim Your Face Campaign, <https://reclaimyourface.eu>.



that deploys subliminal techniques beyond a person’s consciousness in order to materially distort a person’s behaviour in a manner that causes or is likely to cause that person or another person physical or psychological harm’. Article 5(b) also prohibits ‘the placing on the market, putting into service or use of an AI system that exploits any of the vulnerabilities of a specific group of persons due to their age, physical or mental disability, in order to materially distort the behaviour of a person pertaining to that group in a manner that causes or is likely to cause that person or another person physical or psychological harm’. Much greater analysis and discussion is required into the implications of these draft prohibitions and whether they are sufficient or require extension in the field of social care, particularly with regard to instances in which the use of new and emerging technologies inhibits choice and control, restricts cognitive autonomy or results in a new form of substitute decision-making.¹⁷⁰

For other technologies, such as so-called ‘companion’ robots, their use or provision by states or private care organisations may not be subject to an outright ban, but may be conditional on their integration with wider strategies and policies aimed at preventing isolation and segregation and increasing connectivity and inclusion within the community, and never as a replacement to fostering human connection.

D. The Establishment of Clear Safeguards

Beyond AI red-lines, the development of clear safeguards is needed in both the decision-making process to introduce new and emerging technologies into social care as well as the establishment of effective oversight and monitoring systems and complaint processes. As we have recommended in previous research by the Human Rights, Big Data and Technology Project, such an approach should be informed by international human rights standards and norms and ensure the meaningful participation of older people.¹⁷¹

1. Meaningful consent

Where technologies are used in older peoples’ lives, this report has underscored that it must be with their meaningful consent and not at the direction of others, even if with a benevolent purpose, such as to increase

¹⁷⁰ European Commission, ‘Proposal for a Regulation of the European Parliament and of the Council Laying Down Harmonised Rules on Artificial Intelligence (Artificial Intelligence Act) and Amending Certain Union Legislative Acts, COM/2021/206 final (21 April 2021).

¹⁷¹ McGregor et al (n6).

security or safety. As discussed further below, meaningful consent cannot be given if the person does not have detailed but accessible information on the benefits and functionalities of the technology as well as the full risks. If in the context of formal care, technology cannot be presented by state or private caregivers as an ‘either/or’ situation, meaning that older people must also be provided with a non-technological alternative, if consent is to be meaningful. They must also always have the opportunity to change their mind and decide they no longer want the technology within their lives, without any adverse consequences to their care and support.

Where individuals are deemed to ‘lack’ legal capacity, they must be supported in their decision-making about the role of technologies in their lives rather than having their decision-making capacity removed from them through substituted decision-making. Moreover, it is possible that some individuals consent to the role of new and emerging technologies in their lives within advanced care directives. However, much more work is needed to examine the specificity that would be required within such directives, particularly as the nature and intrusiveness of specific technologies vary depending on factors such as the model used, the actor implementing it, and the governance and regulatory framework. Moreover, technologies are constantly evolving.

2. Transparency and Safeguards by Companies Designing, Developing and Selling ‘Ageing Tech’

As highlighted by this report, new and emerging technologies may be purposefully developed for older people, often referred to as ‘age tech’, or used as part of care and support, even if not marketed for that specific purpose. In both cases, this report cites research finding that older people feel excluded from the conceptualisation and design of these technologies with the result that they may not be fully and effectively designed and developed to enable them to live high-quality lives. In this regard, a key recommendation arising from this research is for both ‘age tech’ and technology companies more broadly to involve diverse groups of older people in the conceptualisation and design of new and emerging technologies to ensure that they are developed to maximise their goals, needs and interests and adverse human rights impacts are identified and addressed at an early stage.

As highlighted in the report, the creation of opportunities to test new and emerging technologies and the provision of detailed but clear and usable information on how to use the technology to its full extent and



protect human rights, in easy to read and accessible formats, would enhance the prospects of such technologies advancing, and not harming, human rights. Help desks staffed by humans would also facilitate the accessibility and useability of such technologies.

3. Transparency and Safeguards by Private and State Care Providers

At the stage at which local government or private care providers are considering offering new and emerging technologies, the reasons for such a proposal should be publicly documented, making clear whether the proposals are to meet objectives such as cost-reductions, and whether they are aimed at replacing an existing service or as additions to the care and support already offered. An impact assessment should also be carried out to assess the potential impact the technology could have on the safety, security, and human rights of older people and other people who come into contact with that person, such as family members, friends and care workers or informal carers. The design of impact assessments should involve older people and their advocates to ensure the tailoring of the assessment to the human rights of older people.

The impact assessment should not refer to the type of technology generically, such as acoustic listening, but the actual product or model being considered. It should include a comparison with the features of other technologies capable of carrying out a certain function, such as monitoring for falls, in order to see the range of technological options available and their advantages and disadvantages. It should also include assessments of whether specific features, such as collection of data, or the use of cameras or facial recognition, are the only way in which to meet a particular goal and whether they are necessary for the technology to function or an additional feature for commercial benefit or to feed into other goals of the state.

Where the technology will be offered by a private company, as is often the case, the human rights of older people should feature centrally in the procurement process and a risk assessment into that company carried out from this perspective. Consideration should be given to whether any data gathered should be accessible, shared, and usable by the care provider, any other state actors or third-party actors, or the company providing the technology. Such assessments should not simply be between the care provider and the technology provider but should involve meaningful stakeholder consultation, particularly with those who are to use the



technology, or have it used in their lives.¹⁷² As noted above, the use of the technology in an individual's life will require separate meaningful consent and include the right to refuse the use of technology in their lives or to require its removal, without consequence or to the detriment of their care.

Local government and independent care providers should also have ongoing monitoring and oversight practices in place, including for independent regulatory bodies, such as national human rights commissions, care commissions, national preventive mechanisms and independent monitoring mechanisms under the Convention on the Rights of Persons with Disabilities to ensure that the use of technologies complies with human rights, alongside effective and accessible complaints mechanisms.

However, the establishment of such safeguards is a minimum requirement to protect older people's human rights. If new and emerging technologies are to play a role in enhancing or securing the enjoyment of human rights, much greater attention is needed into the types of processes required to ensure that older people are effectively supported, where necessary, to make autonomous decisions about the use of new and emerging technologies in their lives and to exercise meaningful choice.

¹⁷² UNHRC, 'UN Guiding Principles on Business and Human Rights' (2011) UN Doc A/HRC/17/31 (UNGPs), Principle 18.



E. RIGHTS-ENABLING OR A NEW FORM OF COERCION AND CONTROL? POINTS FOR INDIVIDUALS, FAMILIES AND SUPPORT NETWORKS CONSIDERING USING NEW AND EMERGING TECHNOLOGIES

Our report argues that manifold factors influence whether new and emerging technologies offer a tool to enhance enjoyment of human rights as we get older or whether they represent a new form of coercion and control. Here we offer some points for people to take into account when considering possible roles for technology in our lives. These indicators are suggestions and we do not claim that they are complete or exhaustive. Rather, we offer them as a starting point but hope that others will build on them as experience grows within different communities testing and using different technologies in their lives.

Path 1: the potential for new and emerging technologies to support our human rights as we get older increases if:

- 1) The decision that a specific technology may support people to achieve a defined objective is made by the person, not on behalf of them, with support where appropriate;
- 2) the technology is accessible, both in terms of cost and design, and through digital literacy initiatives which extend beyond the 'basics' to include support on how to maximise the use of all of the features of the technology without over-promising or exaggerating what the technology is capable of doing;
- 3) tech providers and state and independent care providers are fully transparent about how the technology captures, processes (including through the use of data analytics), stores, shares, and sells data, with whom, and in what form, with clear examples, such as how it might be used in healthcare or insurance decisions and which types of actors might be able to access sensitive medical data. They explain in a clear and understandable way, the options that exist – and do not exist - to prevent data being captured and used in ways we may not want, including to make decisions about our lives, and how it can be deleted;
- 4) opportunities are offered to people to test and trial individual pieces of technology and smart homes before deciding to introduce them into people's home;



- 5) people are able to tailor settings and functions to their needs, rather than having to 'give up' data, for example, by default;
- 6) people have choice of different products rather than having to decide on whether to use one fixed product to meet a particular goal and are given non-technological options, so that we are not in a 'take-it-or-leave-it' position over our care or support if we decide we do not want technology in our lives;
- 7) there has been investment in the development and dissemination of technologies that are shown to decouple choice of living arrangements from access to support; by giving people greater control over their own support; by enabling support providers to achieve greater economies of scale; and by reconciling the management of risk with the promotion of independence';
- 8) people are able to stop using the technology, or having it used in the context of their care and support, if they change their mind or feel it does not serve their goals without any adverse implications for their care and support;
- 9) there are clear and accessible ways to make complaints about the technology itself or how different actors, including state agencies, independent care providers and health workers, access the technology or make decisions based on the data it collects;
- 10) the technology is used in a context in which (a) social care is based on equality and human rights, emphasising principles of dignity, fairness, participation and empowerment, and focuses on supporting us to live independently and be included in the community and to be in control of decisions about our lives; and (b) the technology sector is regulated in a way to enable rather than put human rights at risk.



Path 2: the potential for new and emerging technologies to put the human rights of older people who draw on care and support at risk increases if:

- 1) new and emerging technologies are introduced into people's lives by someone other than the person, without their consent;
- 2) the purpose of introducing the technology is not solely or primarily to meet a person's own goals but to meet the objectives of someone else, such as to monitor them or to cut costs in care, such as through reduced staffing;
- 3) the technology has been introduced as a replacement for a previous service that a person valued;
- 4) people are not able to exercise meaningful consent about the introduction of the technology or given the opportunity to opt-out or reject the use of the technology in their lives;
- 5) a non-technological alternative is not provided, leaving people with a 'take it, or leave it' position about the role of technology in their lives and as a result people are denied choice about how they arrange their own care or support;
- 6) Technology companies and state and independent care providers are not transparent about the invasiveness of the technology and how data is captured, processed, stored, shared or used;
- 7) The use of technology takes away or restricts people's choice and control about how they live their lives, for example about whether a person can leave their home, or who they allow in, when they eat, get up in the morning or go to bed at night;
- 8) No routes to challenge the introduction of the technology exist;
- 9) The technology is introduced in a context in which data and new and emerging technologies are poorly regulated, while social care is overwhelmingly about maintaining people and is transactional in nature rather than about supporting people to live their best lives.



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