

# THE HUMAN RIGHT TO SOCIAL CARE

**A POTENTIAL FOR SCOTLAND**



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# INTRODUCTION

Scotland has a long and positive track record in seeking to embed and promote a culture of human rights in all parts of society. This positive approach was enshrined in the Scotland Act[1] which created the Scottish Parliament itself and which ensured that no legislation would be passed by the new body which would not be compliant with the requirements of the European Convention of Human Rights.

This positive framing saw the creation of the Scottish Human Rights Commission in 2008 enacting the provisions of the Scottish Human Rights Commission Act 2006.[2]

More recently there has been cross political party consensus in opposing attempts to reduce the powers of the Human Rights Act and whilst these responses have varied they have resonated with a generally positive social milieu which views the upholding and furtherance of human rights as intrinsic to what it means to be a citizen of Scotland.

Perhaps the embedding of human rights within the popular and practice context has been felt most acutely within the social care and health sectors. In 2017 Scotland adopted a new set of Health and Care Standards[3] which are unashamedly human rights in origin and ethos. The scrutiny and inspection models based on these commenced in July 2018 [4] and again seek to emphasise the fulfilment and realisation of human rights within the care delivery context.

However, there is some distance to go before we can be assured of the ability to fulfil all the human rights which belong to us as citizens, not least in health and social care.

There is, nevertheless, a distinction between a human rights-based approach to an issue or topic and an articulation of that field as a distinctive human right underpinned by international law. This is in part reflected by the Report of the First Minister's Advisory Group on Human Rights Leadership in December 2018.[5] That Report paved the way for the establishment in June 2019 of a Task Force on Human Rights. [6] The primary aim of this group is to bring forward legislation which will seek the incorporation of the United Nations Convention on Economic, Social and Cultural Rights (ESCR) into Scottish law.

This paper will argue that should Scotland incorporate the United Nations Convention on Economic, Social and Cultural Rights then this provides the Scottish legislature with a tremendous opportunity to give some real legislative grounding to the delivery of the 'right to health' and more especially what we will argue is by extension the 'right to social care' in Scotland.

In what follows this paper will briefly explore:

- The development of the concept of the 'right to health' in both international treaties, UN bodies and in international case law.
- The concept of the 'right to health' as it relates to a definition of 'social care' and 'long-term care.'
- The articulation of 'social care' and 'long-term care' as a distinctive human right, and
- What this might mean for social care practice.

# THE RIGHT TO 'HEALTH'

The right to health has for some considerable time been recognised as a fundamental human right. This process of recognition began as far back as 1946 when the World Health Organisation (WHO) stated in the preamble to its founding constitution when it defined health as:

"a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." [7]

In its elucidation of what this means the WHO stated that this meant that there were government-provided social measures which were required to ensure adequate health. In what has been called the first formal declaration of health as an inalienable human right [8], the WHO stated:

'the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.'

The right to health whilst not central to the 1948 United Nations Universal Declaration of Human Rights still nevertheless plays a significant role in that Declaration's envisaged realisation of rights. Within the UNDHR, Article 25 states that:

"Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.' [9]

Elsewhere within the UN Declaration Article 8's defence of the right to personal and psychological integrity clearly stretches into the health and social care domain, so too are its additional accommodations for security in case of physical debilitation or disability and its special mention of care for women and babies both pre and post-natal.

However, the right to health finds its fullest articulation within the 1966 International Covenant on Economic, Social and Cultural Rights. (ESCR) [10] [11]

ESCR in its most direct and explicit description of the right to health in Article 12 states:

- '1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.
2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:
  - (a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;
  - (b) The improvement of all aspects of environmental and industrial hygiene;
  - (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
  - (d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.'

This articulation has been further advanced through case law but more directly in the UN General Comment no 14 in 2000.

In 2000, the United Nations' Committee on Economic, Social and Cultural Rights issued General Comment No. 14, which sought to address what it described as "substantive issues arising in the implementation of the International Covenant on Economic, Social and Cultural Rights" with respect to Article 12 and "the right to the highest attainable standard of health." [12] The General Comment provides more explicit language on the freedoms and entitlements included under a right to health.

Its opening paragraph robustly places the right to health as critical and central to the realisation of other human rights:

'Health is a fundamental human right indispensable for the exercise of all other human rights. Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity.'

The General Comment makes the direct clarification that "the *right to health* is not to be understood as a *right to be healthy*." It argues that Article 12 tasks the State with recognising that each individual holds an inherent right to the best feasible standard of health, and it goes on to delineate some of the 'freedoms from' and 'entitlements to' that accompany such a right.

The General Comment recognises the changing health demographics and also the changes to the definition of health since its earliest articulation in the 1940s. This is evident in section 10 which states:

'10. Since the adoption of the two International Covenants in 1966 the world health situation has changed dramatically, and **the notion of health has undergone substantial changes and has also widened in scope**. [13] More determinants of health are being taken into consideration, such as resource distribution and gender differences. A wider definition of health also takes into account such socially-related concerns as violence and armed conflict. Moreover, formerly unknown diseases, such as human immunodeficiency virus and acquired immunodeficiency syndrome (HIV/AIDS), and others that have become more widespread, such as cancer, as well as the rapid growth of the world population, have created new obstacles for the realization of the right to health which need to be taken into account when interpreting article 12.'

For our purposes there is a critical emphasis within the Comment on the role of the citizen in exercising choice, control and participation in matters relating to health and wellbeing:

'A further important aspect is the participation of the population in all health-related decision-making at the community, national and international levels.' (11)

[The articulation of a wider 'social definition' of health and wellbeing is also seen in what the General Comment states at section 25 for older persons:

'25. With regard to the realization of the right to health of older persons, the Committee, in accordance with paragraphs 34 and 35 of general comment No. 6 (1995), reaffirms the importance of an integrated approach, combining elements of preventive, curative and rehabilitative health treatment. Such measures should be based on periodical check-ups for both sexes; physical as well as psychological rehabilitative measures aimed at maintaining the functionality and autonomy of older persons; and attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity.'

The United Kingdom is a signatory to ESCR which means that we are bound in international law, to protect the right to health and its 'progressive realisation' [14], which means the UK must take steps towards achieving this right to the maximum of its available resources.

Nearer home the European Convention on Human Rights does not explicitly guarantee a right to health care or a right to be healthy. However more recent case law is evidencing a growing and developing willingness on behalf of the European Court of Human Rights to rule and comment on the right to health and what that means in terms of both the individual and the State's duties and obligations. As a preamble reviewing recent cases in this area has stated [15]:

'The Court is thus inevitably called upon to consider cases having a socio-economic dimension, including health, where they raise an issue under one or more fundamental civil and political rights guaranteed under the Convention. Consequently, health issues have arisen before the Court in a wide variety of circumstances.'

In a similar vein Lewis Graham has commented on the emerging work of the European Court in this area, cautiously stating: [16]

'It must be reiterated that the Court has not carved out a freestanding 'right to health' from Article 2. These cases are limited to specific factual situations in which a death has occurred (although Article 2 is not limited to this, as it explained in *Atiman v Turkey*). Nonetheless, these cases represent a significant development of a European right to health, moving beyond the theoretically interesting dicta in the Cyprus case and into a more substantive justiciable protection.'

Alongside this more frequent articulation of the right to health has been a debate around the negative and positive elements of the right. We will not explore this in depth in this paper, but it is important in this regard to see the work of international scholars such as Professor Paul Hunt as attempts to see obligations around the right to health as positive duties. Hunt argues that there are positive rights encompassed within the right to health such as the responsibility of society to pay special attention to the health needs of the underserved and vulnerable, which are included in the right to health.[17]





# THE NATURE OF SOCIAL CARE

From the above the reader will note that there has been significant development in the re-defining of what the right to health might mean. It is our argument that, far from being a recent phenomenon, the description and delineation of the right to health as something which is holistic and *more than* just a right to physical and physiological health has a long history within international law and practice. This *holistic right to health* includes the right to the fullest realisation of health and well-being. It is our contention that such a right includes ipso facto the right to what has come to be known in the United Kingdom as ‘social care’ but which variously and internationally has been described as a right to ‘social services’ and ‘long-term care.’

Support for such a position is evident in the proceedings of the United Nations Open-ended Working Group on Ageing (OEWGA).

In December 2010, the United Nations General Assembly established an open-ended working group open to all States Members of the United Nations for the purpose of strengthening the protection of the human rights of older persons.[18] The main focus of the working group is to consider the existing human rights framework in relation to older persons and to identify possible gaps and how best to address them.[19]

The Open-ended Working Group on Ageing has met on numerous occasions since its inception. Its work has evidenced the emergence of the right to health as one of significance within the human rights landscape and its work is also illustrative of a move towards a much more holistic and non-clinical understanding of health and well-being. The OEWGA has most recently begun to explore the issues of “autonomy and independence” and “long-term and palliative care.” Indeed, a considerable part of its ninth session in July 2018 was dedicated to receiving evidence and holding a panel session on ‘long-term care’ and palliative care.[20] This is illustrative of a growing international articulation both in terms of what comprises and constitutes the right to health but most especially what one should consider as being intrinsic to the right of social care and long-term care.

So, what is this social care that this paper is suggesting is intrinsic to the right to health?

A great deal of contemporary policy and political debate in Scotland has tended to lead to a conflation, sometimes accidental, sometimes deliberate, of what health and social care services are and what they seek to deliver. The equating of the two is damaging and unhelpful. In order to understand how social care (or long-term care) can be viewed as a human right we need to understand what it is and what it is not.

There are many definitions, both legal and practice based, as to what social care is. Importantly, for instance, social care whilst it may contain services and behaviours which are clinical or medical in nature is not primarily about one’s physiological health.

Scottish Care has defined social care as:

‘The enabling of those who require support or care to achieve their full citizenship as independent and autonomous individuals. It involves the fostering of contribution, the achievement of potential, the nurturing of belonging to enable the individual person to flourish.’

In essence social care is about enabling the fullness of life for every citizen who needs support whether on the grounds of age, disability, infirmity or health. Social care and support are holistic in that it seeks to support the whole person and it is about attending to the individual's wellbeing rather than simply their physiological health. It is about removing the barriers that limit and hold back and the fostering of conditions so that individuality can grow, and the independent individual can flourish.

Social care is not about performing certain functions and tasks alone for it is primarily about relationship; the being with another that fosters individual growth, restoration and personal discovery. It is about enabling independence and reducing control, encouraging self-assurance and removing restriction, maximising choice and building community.

Therefore, as many of us have sought to illustrate over the last few years, social care is not equivalent to health but a critical component to the achievement of health and wellbeing and the realisation of the human right to health. It is in this realisation to the right to health that social care finds its place and space. Social care is profoundly about human rights. It is about giving the citizen **control and choice, voice and agency, decision and empowerment**. These sentiments are well reflected in the international literature both on the role and purpose of social care [21] – especially independent living and its acceptance as a human right – and in what has been written about ‘long-term care.’

The remainder of this paper will explore three instances where the ‘human right to social care’ has already impacted within the legislation of Scotland or has the potential to do so. Thereafter we will consider some general characteristics which may form part of a developing human right to social care.



# PRACTICAL INSTANCES OF THE 'HUMAN RIGHT TO SOCIAL CARE'

## SELF-DIRECTED SUPPORT

Within the Scottish context all of the above is very well expressed within the Self-directed Support (SDS) legislation and its accompanying Statutory Guidance. [22]

The SDS legislation in Scotland unapologetically grew out of the independent living movement of the learning and physical disabled communities in the 1970s. With the closure of large-scale institutions there was an emphasis on enabling individuals to live more independent lives. Policies and practice at the time and since emphasised the importance of building social care supports around the life of the individual rather than expecting the individual to fit into what services were available. A one size fits all approach was replaced by the urge to develop and offer bespoke individual services and supports.

In Scotland this process was encapsulated in policies such as 'The Same As You?' (2000) [23] and in 'Our Shared Vision for Independent Living in Scotland.' (2013). [24] The vision of the latter declared that Independent Living was about choice, control, freedom and dignity.

In Scotland this was articulated further in the reform of direct payments and in the ten-year strategy, 'Self-Directed Support: A National Strategy for Scotland'. [25]

The Social Care (Self-directed Support) (Scotland) Act 2013, is a direct continuation of this earlier work on personalisation. The pursuit of citizen control, independent living, autonomy and choice evident in recent international human rights debates, practice and documents is clearly not a recent one. It is the pursuit which lies at the heart of the disability civil rights movement and the realisation of human rights – even before the emergence of the UN ESCR.

The Self-directed Support legislation seeks to enshrine in Scottish law and social care practice the core human rights values of inclusion, contribution and empowerment through real choice and respect. The legislation is underpinned by a set of core values which at times mark the link between social care legislation and day to day practice.

The following words describe the values that have helped to inform the Statutory Guidance: [26]

- Respect
- Fairness
- Independence
- Freedom
- Safety

It will be clear that such values are rooted in the earlier concepts of personalised services and greater independent living.



The Act and Guidance then go on to indicate that there are certain core principles at the centre of self-directed support. Principles are described as ‘..... the means by which we put our values into practice. The 2013 Act (Sections 1 and 2) provides four legal principles: [27]

- Participation and dignity
- Involvement
- Informed Choice
- Collaboration.

The Guidance then goes on to root these principles and values within a human rights-based framework. The Guidance reflects the conviction that the provision of social care and the facilitation of choice as part of this, is a way of protecting and realising the human rights of those in receipt of care and support.

Effective, person-centred social care, determined and led by the individual in partnership with the relevant professional increases the choice for the supported person and provided them with the opportunity to take more control and manage their life.’ [28]

The Act and its Guidance envisage various ways in which the values and principles are put into effect. In practice this means that there needs to be as much emphasis placed upon the universal needs of an individual as much as attending to their basic needs. There is a clear distinction between addressing needs which keep you alive and healthy and those which are more holistic and relate to well-being. To remain in relationship, to maintain friendships and be connected up to the community are as important requirements of support as being nourished, healthy and safe. This is the territory where the right to health is realised through the human right to social care supports and care: [29]

‘Participation and dignity are core aspects of independent living whereby all supported people should expect to have the same freedom, choice, dignity and control as other citizens at home, at work and in the community. In some respects, the concept of independent living provides a modern interpretation of the social welfare duties provided in the 1968 [Social Work Scotland] Act.’

## CHOICE

The work of the United Nations Open-ended Working Group on Ageing (OEWGA) has emphasised ‘autonomy and independence’ as core elements in the achievement of the right to health. These, we would argue, find real explication in the Self-directed support Act and its Guidance and what they state not only about independent living and support but most specifically about choice

Informed choice is critical to the implementation of a human rights-based approach to SDS. Choice is very different within the social care context compared to the health environment.

If I have a medical emergency then personally I want the best clinical care and don’t really want to have much say in who delivers that care as long as they are trained, suitably qualified and supervised. A short term stay in a hospital is very different from the place and people with whom I spend my life. If I am living with a lifelong condition or need support in any way because of life circumstances or age then I most certainly do want to have more choice and control both over who is in my life as a carer and what the nature of that support and care might be. The critical importance of legislation like the Self-directed Support Act is it’s embedding within statute of these basic rights to control and choice about my person and body, and the care and support I receive. It is they that critically enable well-being and the realisation of my right to health.

# DEVELOPING THE CHARACTERISTICS OF A HUMAN RIGHT TO SOCIAL CARE

If social care was considered to be a fundamental human right then this would have considerable significance for the way in which it was viewed. All too often social care is perceived through the lens of its relationship with acute health services and its impact upon those, e.g., the failure to provide social care support packages considered from the perspective of the impact on A&E waiting times and delayed hospital discharges. Were social care to be considered from the perspective of being inherent to the achievement and realisation of all other human rights then the perspective would be a considerably altered one. There would be both an imperative to address issues from a human rights-based approach but even more than that there would be a requirement to address areas where the right to social care was being prevented or challenged by existing practice and if necessary with the potential of exercising legal redress. In the remaining part of this paper we identify some (but by no means all) of the areas where some of this reconsideration might impact.

## BUDGET AND FINANCE

One of the major issues facing the practice of social care is delivering that care and support in the face of fiscal restriction and in most recent times in Scotland in the light of austerity. A human rights-based approach to the setting and delivery of budgets both at national level but also at the local administrative level where decisions are made on the allocation of local resources would have a profound impact upon social care. Such a process of budgetary impact assessment and decision-making has been articulated most recently by the Scottish Human Rights Commission.<sup>[30]</sup> There is little that can be achieved at local level and certainly at the point of a local social worker making fiscal decisions if there is already an inadequacy of resource to meet the rights of individuals.

## DECISION MAKING

Closely related to the issue of fiscal allocation in social care are the diverse mechanisms and models used to determine those who are considered to be 'eligible' to receive social care support especially if that support and care is funded by the State. Such eligibility models operate in many jurisdictions and most recently within Scotland the level at which an individual can be in receipt of funded social care has risen to its highest ever. Such a process has a significant impact on the ability of individuals to access care and their ability to exercise their human right to support, independence, health and well-being. A human rights-based approach to the nature of these decisions would be of immeasurable benefit. In addition, the process of decision-making also impacts upon issues such as capacity especially mental health capacity. For tens of thousands of individuals living with Alzheimer's disease and similar limiting neurological conditions, a human rights-based approach to decision-making, to issues of legal capacity and the exercise by the State of control and therefore the removal of personal autonomy, have profound ramifications upon individual lives. The critical role of participation, involvement and engagement of citizens impacted by decision-making should be at the centre of the articulation in practice of any human right to social care.

# SERVICE DESIGN AND USE OF TECHNOLOGY

Social care is necessary for the fulfilment of health and well-being for tens of thousands of individuals. The nature of support services which are required to ensure that an individual is able to exercise their rights of autonomy and independence have changed over the decades. In particular the growing consensus around independent living sits at the heart of the delivery of many systems of social care, not least in Scotland. One of the areas which is alive with human right challenges is the extent to which technology and digital interventions can be utilised to support and enable the achievement of a human right to social care. For some the issues of privacy, autonomy, personal choice and control, even personal independence far from being assisted by the use of technology in their own home or 'homely setting', can lead to the removal or restriction, and diminution of basic human rights. Scottish Care has been working with other stakeholders to articulate what a rights-based approach to the use of technology and digital interventions might look like in a social care environment.[31]

## WORKFORCE

The social care workforce in Scotland is predominantly female (86%) and organisations like Scottish Care have long argued that the way in which that workforce is treated in terms of fair work practices, equal pay and other related matters is often one rooted in a discriminatory approach and is evidence of gender segregation. Viewing issues of workforce, its selection, deployment and treatment through a human rights lens would have a significant impact especially if the issue of gender segregation was recognised as in itself one of the discriminatory determinants of unequal and unfair treatment of the social care workforce.

## PALLIATIVE CARE

One of the most recent attempts to develop a human rights approach to an element of social care and health has been the work around palliative and end of life care.

There is a long history of seeking to articulate a human right to palliative care based upon the ESCR right to health. This has included a whole host of academic articles, international statements and declarations and a developing range of case law. It is itself illustrative of the way in which a critical component of the practical delivery of social care is already viewed by many as inherently a distinct human right in its own entity.[32] The right to palliative care is most commonly defined through its relationship to the realisation and fulfilment of the right to health as well as relating to the right of equality, protection from inhuman or degrading treatment, the right to autonomy and bodily integrity.

# CONCLUSION

This paper has sought to argue that the human right to social care is an intrinsic part of the right to health. It has further sought to posit the nature of that right in terms of the exercising of choice and control, independence and autonomy in social care or long-term care and to evidence this through the example of Self-directed Support in the Scottish context. It has further argued that a human right to social care has potential for various key components of social care which are themselves enabling of the realisation of the right to health.

In doing so we acknowledge that there is also an emerging and valid view which has contended that social care should be seen as a distinctive human right separate from the right to health.

Social care and long-term care are arguably distinctive rights in themselves even if one accepts that they are subsumed within a holistic understanding of the 'right to health.' Such a perspective has been advanced by Gruskin et al who argue that the human rights expressed in the UNDHR establishes a:

"responsibility [that] extends beyond the provision of essential health services to tackling the determinants of health such as, provision of adequate education, housing, food, and favourable working conditions," further stating that these provisions "are human rights themselves and are necessary for health." [33]

Regardless of the perspective taken we hope that the reader will recognise and agree that social care is a human right and is one that enables, facilitates and empowers the realisation of our human rights as a whole. The potential of this distinctive human right and its articulation within any new human rights-based legislation in Scotland should not be ignored.





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- [30] The Scottish Human Rights Commission has published an immeasurably helpful set of papers on the practicalities involved in establishing a human rights-based approach to budget setting and resource allocation. See <http://www.scottishhumanrights.com/economic-social-cultural-rights/human-rights-budget-work/>
- [31] A Human Rights Charter for Technology and Digital in Social Care and Guidance Document on the Human Rights Charter for Technology and Digital in Social Care, Scottish Care, 2019. See <https://scottishcare.org/wp-content/uploads/2019/11/Guidance-Document-for-Human-Rights-Charter-for-Technology-Digital-in-Social-Care.pdf>
- [32] There is a wide range of articles and Charters in this space. See especially The Korea Declaration. Report of the Second Global Summit of National Hospice and Palliative Care Associations, Seoul, March 2005. [http://www.worldday.org/documents/Korea\\_Declaration.doc](http://www.worldday.org/documents/Korea_Declaration.doc) and the 2013 Prague Charter, see The Prague Charter: Urging governments to relieve suffering and ensure the right to palliative care, Lukas Radbruch, Liliana de Lima, Diederik Lohmann, inter alia, 2013, <https://journals.sagepub.com/doi/full/10.1177/0269216312473058>. For the seminal work in this area see Palliative Care as an International Human Right, Journal of Pain and Symptom Management Vol. 33 No. 5 May 2007, Frank Brennan, [https://www.jpsmjournal.com/article/S0885-3924\(07\)00155-8/pdf](https://www.jpsmjournal.com/article/S0885-3924(07)00155-8/pdf)
- [33] See Gruskin, Sofia; Edward J. Mills; Daniel Tarantola (August 2007). "History, Principles, and Practice of Health and Human Rights". The Lancet. 370 (9585): 449–455. [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(07\)61200-8/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(07)61200-8/fulltext)

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