

REVISED
EDITION

Being Human:

A human rights based approach to health and social care in Scotland



ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

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Foreword

The existing policy and strategic framework of human rights protections for people in Scotland is largely considered to be robust. However, what we often hear about people’s experiences of support and services fails to fully reflect this agenda. It is clear that putting a Human Rights-Based Approach into practice still remains a challenge for people who use support and services, as well as for commissioners and providers. Scotland’s National Action Plan for Human Rights (SNAP) sets out a progressive roadmap towards a country where everyone can live with human dignity. It is based on a wealth of evidence about how people experience their rights, in a range of settings throughout Scotland.

Health and social care have a significant role to play in the enjoyment and protection of human rights – particularly for people who are disabled, people who live with long term conditions and unpaid carers. In this context, the fulfilment of human rights mean that people enjoy autonomy, self-determination, the opportunity to actively participate in decision-making that affects their lives – rather than government structures or other public bodies deciding what is good for them – and access to redress when things go wrong. This Think Piece acts both as a well-timed discussion of some of the progress we have made and a warning that our commitment to the fundamental principles and values enshrined in human rights laws and international obligations are being tested. We must not allow regressive changes to slip through, nor opportunities to improve people’s lives to be missed.



Judith Robertson
Chair

Scottish Human Rights Commission

Human rights are the basic rights and freedoms that belong to every person in the world. Based on core principles that include dignity, fairness, equality, respect and autonomy, human rights protect our freedoms to control our own lives. Taken together with Britain's Equalities legislation – and the requirements of the Public Sector Equality Duty – human rights provide a powerful framework for change to which Scottish public services must respond. The challenge is to make these rights a reality – to move beyond simple compliance and embrace the spirit of this legislation, so that human rights become active considerations for those who deliver public services and are at the forefront of every interaction.

Our job at the Equality and Human Rights Commission is to help make Britain fairer. We do this by safeguarding and enforcing the laws that protect people's rights to fairness, dignity and respect. As a statutory non-departmental public body established by the Equality Act 2006, the Commission operates independently from Government, providing it with expert analysis on equality and human rights, and using robust evidence to challenge its decision-making when appropriate. Our priorities are based on a robust evidence base – the EHRC's Equality and Human Rights Measurement

Framework – which sets out the key inequalities that people face in Scotland. These include:

1. Raising standards and closing attainment gaps in education.
2. Encouraging fair recruitment, development and reward in employment.
3. Supporting improved living conditions in cohesive communities.
4. Encouraging democratic participation and ensuring access to justice.
5. Ensuring that all people can access the health services they need.
6. Tackling harassment and abuse of people who share particular protected characteristics.

These are priorities that I know will be shared by the ALLIANCE and its supporters, who are key in working with us to make these rights a reality.



Alastair Pringle
Executive Director
Equality and Human Rights Commission

Introduction

In this revised and updated Think Piece, the ALLIANCE seeks to contribute to the continuing conversation on human rights in Scotland, and particularly how they apply to health and social care and people who are disabled and living with long term conditions. We hope it will help to stimulate discussion and add to the growing body of work in this area.

Human rights are a set of universal, non-political, binding, international standards. They are inherent to all human beings, irrespective of our nationality, race, gender, sexual orientation, disability, religion or any other status¹.

Several principles underpin human rights; for example, they are indivisible, interrelated and interdependent. This means that all rights have equal status and fulfilment of one depends – either partly or in whole – on others². Another principle is that, by signing up to international human rights treaties, Governments commit to a triple duty to respect, protect and fulfil human rights. This means that the State must not simply refrain from directly interfering with our rights or protect us from interference by others; it also means the State has an obligation to take pro-active, positive steps to facilitate the enjoyment of everyone's rights³.

However, for many people in Scotland – including

people who are disabled and living with long term conditions – human rights remain unrealised⁴. For example, there is still some way to go to ensure that people consistently enjoy their right to care, treatment and support that is timely, available, accessible, acceptable, and of a good quality. Furthermore, too many people still experience obstacles to their full, meaningful and active participation in decisions that affect them. This extends not just to their own care, but more widely into decision-making on the design, delivery and resourcing of services and support. Despite much work to address stigma and discrimination, this is still a part of everyday life for many people who are disabled and living with long term conditions, including within health and social care support settings.

Despite many checks and balances incorporated in law, guidelines and practice, there is still inadequate redress when rights are infringed. Public bodies are often unaware that they are interfering with people's rights, while at the same time people are not actively informed that they have rights and often don't know how to access them.

This is a crucial time for human rights in Scotland. The 2013 creation of Scotland's National Action Plan for Human Rights (SNAP)⁵ has already gone some way to increasing



awareness and understanding of rights-related issues, including in the sphere of health and social care, and how rights pertain to people who are disabled and living with long term conditions. As the current Chair of the Scottish Human Rights Commission, Judith Robertson, notes in her Foreword, SNAP is a roadmap towards a Scotland where everyone can live with human dignity and where international

human rights are realised in everyday life. Its role is to help promote, support and develop strong rights-based policy and strategy and the implementation of rights in practice. As we demonstrate in this paper, SNAP is one of several national initiatives that currently provides us with exceptional opportunities to promote and mainstream human rights and the rights-based approach throughout Scotland.

Recent history of human rights in the UK and Scotland

1948 – The Universal Declaration of Human Rights (UDHR) is agreed by the UN General Assembly.

1950 – The European Convention on Human Rights (ECHR) is agreed by the Council of Europe, committing signatories to respect and ensure civil and political rights. The UK has been bound by the ECHR since 1953.

1965 – The United Nations adopts the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD), which the UK ratifies in 1969. ICERD protects the rights of all people to enjoy civil, political, economic and social rights, without discrimination on grounds of race, colour, descent or national or ethnic origin.

1966 – The United Nations adopts the International Covenant on Economic, Social and Cultural Rights (ICESCR) and the International Covenant on Civil and Political Rights (ICCPR). The UK has been legally bound by both since 1976.

1979 – The United Nations adopts the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW). This treaty focuses specifically on equality between women and men in all areas of life. The UK ratified CEDAW in 1986.

1989 – The United Nations adopts the Convention on the Rights of the Child (CRC), to which the UK has been bound since 1991, providing for a range of rights, including the right to have a say in decisions and specific rights for children who are disabled.

1998 – The UK Human Rights Act (HRA) passes, allowing the ECHR to be incorporated into domestic law. The HRA also aims to bring about a cultural shift towards respect for human rights, including placing them at the heart of public services. The 1998 Scotland Act is also enacted, establishing a new Scottish Parliament and provisions for the protection of human rights within Scotland.

2006 – The United Nations Convention on the Rights of Persons with Disabilities (CRPD) comes into force (UK legally bound since 2009), reaffirming the human rights of people who are disabled and requiring governments to act to remove barriers to these.

2013 – Scotland's National Action Plan for Human Rights (SNAP) launches.

2016 – The Scottish Government publishes its CRPD delivery plan, 'A Fairer Scotland for Disabled People.'

Key international human rights instruments and articles

Universal Declaration of Human Rights (UDHR)⁶

- Article 22 – The right to social security

International Covenant on Economic, Social and Cultural Rights (ICESCR)⁷

- Article 6 – The right to work
- Article 9 – The right of everyone to social security
- Article 11 – The right to an adequate standard of living
- Article 12 – The right to the enjoyment of the highest attainable standard of physical and mental health

United Nations Convention on the Rights of Persons with Disabilities (CRPD)⁸

- Article 12 – Equal recognition before the law
- Article 14 – Liberty and security of the person
- Article 19 – Living independently and being included in the community
- Article 21 – Freedom of expression and opinion, and access to information
- Article 24 – Right to education
- Article 25 – Right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability
- Article 28 – Right to work, on an equal basis with others

The why and how of human rights

We all have rights to the highest attainable standard of health, an adequate standard of living, and to the factors that enable these. But many people who are disabled or living with long term conditions still describe being viewed and treated as of lesser value – if not worse – than their peers⁹¹⁰. However, if developed and delivered in a rights-based way, health and social care services and support provide one means, among others, to ensure everyone can live their life the way they choose, at home, at work and in the community. Without this, many people cannot enjoy the human rights to which they are entitled.

But it isn't just about rights within the context of services and support. Fulfilment of the right to independent living, for example, is a critical tool to enable people to contribute as active citizens, creating an inclusive and equal society. And it isn't just about individual rights, but taking a wider 'rights-based' approach that values the qualities that people who are disabled and people who live with long term conditions have to offer.

If principles of equality and non-discrimination are not, in themselves, enough to respect and protect human rights, there are also clear economic reasons. Realisation of the right to live independently and be included in the community avoids the associated costs of social isolation.

Ensuring the realisation of people who are disabled's right to work has economic benefits for individuals and the potential to reduce the need for support from out of work social security payments.

'Taking a human rights-based approach to social care doesn't get us off the hook of making hard choices on resource allocation, but it does offer more fertile ground in which to embed progress.'

12 Propositions for Social Care ¹¹

As public services in Scotland struggle to reform to meet increasing demand with smaller financial resource, human rights offer a fair and consistent basis to guide policy development, service redesign and resource allocation. This requires human rights principles to be embedded clearly within law and policy and within operational processes and decision-making, including local strategic commissioning.

Public service reform requires far greater understanding of human rights across Scottish society. Human rights have all too often been associated with courts, lawyers and retrospective legal action. It is also not unusual to hear people express the fear that introducing a human rights-based approach will mean people demand entitlements that simply cannot be delivered

in a difficult financial climate. Used effectively, however, rights have the potential to offer us a set of standards that shape policies, programmes and practical interventions, i.e. something that concerns us all in our everyday lives.

The underlying principles of the PANEL approach¹² offer a way to consider how we can put human rights into practice, noting their influence over the design, delivery and assessment of care and support.

The PANEL principles

- **Participation** – How are people actively taking part in decision-making on this issue?
- **Accountability** – How are organisations and people meaningfully accountable for realising human rights in this context?
- **Non-discrimination** – Does this approach recognise that everyone has the same rights (regardless of their characteristics or status)?
- **Empowerment** – How are people acquiring the power to know, understand, and claim their rights in this context?
- **Legality** – Have we made sure that the approach is embedded in law that applies human rights standards?

The SNAP Health and Social Care Action Group¹³ continues to monitor, comment on and support the development of the key policies that contribute to the public service reform agenda – challenging where human rights commitments are made in principle but not evident in practice. After all, this is not just about saying the right thing in a strategy or a Government Bill, but taking action to improve people's lives.



National policy and human rights

Scotland is currently witnessing a time of significant change in a variety of policy areas related to the rights of people who are disabled and people living with long term conditions. Many of these either directly refer to human rights or at least emphasise rights-based approaches, like greater involvement of individuals and communities in responding to the societal challenges that face us.

National Performance Framework (NPF)

The purpose of the National Performance Framework (NPF) is to provide a clear vision for Scotland with broad measures of national wellbeing covering a range of economic, health, social and environmental indicators and targets. In its Programme for Scotland 2016-17¹⁴, the Scottish Government committed to integrate human rights within the NPF, “to help locate human rights at the centre of policy-making and delivery for the Government and the public sector.”

Community Empowerment

The aspiration of the Community Empowerment (Scotland) Act 2015 is to enable communities to exert greater influence or control over things that matter to them, particularly in relation to the way that land and buildings are managed and used. The legislation provides a mechanism for community bodies to put forward their ideas for how services could be changed to improve

outcomes, which could also include community bodies taking on delivery of services.

Social Security

Social security is a fundamental human right that provides for access to payments without discrimination in order to secure protection from social risks and contingencies.

The development of Scotland’s first ever social security system¹⁵ offers the Scottish Government an opportunity to take a rights-based approach to the design, implementation, monitoring and scrutiny of the new system. It has indicated a commitment to taking a rights-based approach to the devolved social security powers, including efforts to tackle the stigmatising and discriminatory culture that has developed towards people in receipt of payments.

Health and Social Care Integration

The legislation underpinning health and social care integration sets out a suite of principles¹⁶, enshrined in law, which are intended to guide how it is delivered throughout Scotland. These principles, and the associated guidance, paint a picture of health and social care that is designed and delivered around people and communities. They require that people are listened to, their expertise valued and that they are influential and able to have choice and control over their own lives. The principles refer to people’s rights and

to their human dignity. They state that health and social care is not simply about sustaining people, but about supporting all of us to participate equally and actively as citizens in our communities.

Similarly, the guidance¹⁷ that accompanies the National Health and Wellbeing Outcomes, against which Health and Social Care Partnerships report and are held to account, is explicitly grounded in a human rights-based approach.

National Clinical Strategy

The National Clinical Strategy¹⁸ outlines the direction of travel for how clinical services in Scotland need to change in order to provide sustainable services fit for the future. The strategy makes the case for stronger participation of people in decisions about their care, and increased co-production with people accessing services in order to support self management.

‘Realistic Medicine’

The Chief Medical Officer’s first Annual Report¹⁹ explains the need for healthcare services in the future to move from the “outdated doctor knows best culture” to one where people accessing services and clinicians combine their expertise and share the power and responsibility of decision-making.

Self Management

In 2008, ‘Gaun Yersel’, the Self Management Strategy for Long Term Conditions in Scotland²⁰, acknowledged that self management supports and encourages people living with long term conditions to access information and to develop skills to find out what’s right for their condition and, most importantly, right for them. This can include a greater understanding of, and ability to exercise, human rights in health and social care settings.

National Care Standards and other ‘Targets’

Standards, targets and indicators are used as measures of performance levels in health and social care systems across the world. They can play an important role in driving improvement and highlighting areas of concern. There can be difficulties with such targets, however, as they can be used as indicators of support and services that do not respect the rights of the populations they serve. Targets must be closely aligned with the rights of people who access support and services and their expectations – not just those of quality assurance within the system. The proposed new National Health and Social Care Standards²¹ are underpinned by human rights principles, while the 2016-17 National Review of Targets²² includes a focus on personal as well as clinical outcomes. Both initiatives provide Scotland with an opportunity to play a leading role in advancing rights-based indicators in health and social care.

Person Centred Care

Person centred care²³ has its origins in alternatives to institutionalisation and developed as a way of including people with complex needs in society by helping to empower them to exercise specific rights, like the right to independent living. This goes beyond notions of compassion, dignity and respect, to support the promotion of people as equal partners in achieving their rights. Recent changes in language and an increase in the use of ‘person-led’ – as opposed to ‘person centred’ – indicates a possible further shift towards a more rights-based approach where people are in the driving seat of their decision-making.

Co-production

Co-production of health and social care, with rights-respecting principles of participation and empowerment at its heart, is a driving factor of Scotland’s 2020 vision for health and social care²⁴. Co-production supports the drive towards prevention, self management and resilience. Person centred care and co-production are not simply ‘nice to have’, but key drivers of reform and improvement in the public sector.

Self-directed Support (SDS)

The national strategy for Self-directed Support (SDS)²⁵ identifies three key areas where human rights principles are demonstrated through SDS: Inclusion - everyone, no matter what level of impairment, is capable of exercising some choice and control in their living, with or without that choice and control being supported by others;

Dignity - everyone is treated with dignity at work, at home and in the community; and Equality - everyone is an equal citizen of the state and has the right to live life as fully as they can, to be free from discrimination and to be safeguarded and protected.

Mental Health

In a 2016 engagement paper on their 10-year vision²⁶, the Scottish Government identified realising the human rights of people with mental health problems as one of eight key priorities for the next Mental Health Strategy. The paper also outlined the aspiration to embed a human rights-based approach across the strategy’s actions, and proposes the PANEL approach as a way of analysing how they deliver on human rights.

Health Inequalities

The right to health is not enjoyed equally in Scotland. As infringements of people’s right to health, health inequalities are the systematic differences in the health of people occupying unequal positions in society, which mean that poorer and/or more disadvantaged people live in poor health for longer and die younger than those who are more affluent. Caused by the unequal distribution of income, power, and wealth, these variations not only highlight our current inability to eradicate a source of national shame, but also represent a significant human rights injustice which Scotland has yet to properly address.

Case studies

Care about Rights

Care about Rights²⁷ is a training and awareness raising resource relating to the care and support of older people developed by the Scottish Human Rights Commission. Care about Rights explains the benefits of applying human rights principles to everyday situations.

The training is designed to increase awareness and knowledge of human rights issues, and give practical advice about how to apply human rights principles in the delivery of care. The approach assists social care staff to involve people accessing services, their families or their advocates in decision-making and deliver more personalised services, thus helping to shift the balance of power in these caring relationships.

The Care about Rights resources look at:

- What human rights are and how they apply to care settings.
- The relationship between human rights and other legislation and standards.
- How human rights can help to balance risks and rights in decision-making.
- How human rights can support the delivery of person centred care.
- How human rights can help resolve conflict and improve communication with people accessing services, their families and others.

Independent evaluation has shown substantial increases in knowledge and confidence among participants in the Care about Rights training. More than half of care staff respondents to the follow-up survey²⁸ felt that the training was helping them to deliver better person centred care and provided a framework for change, by helping older people and their representatives to articulate concerns.

The findings of the interim evaluation of the project also flagged specific challenges faced by the sector in rolling out the key human rights messages, however, such as the pressure on budgets and staff time as well as the need for continued awareness-raising in order for the approach to be adopted by all services.



A Human Rights-Based Approach to Dementia Care

Recent dementia policy in Scotland offers an example of how a human rights-based approach can be applied. Key to this approach has been the participation of people living with dementia and their carers.

The Charter of Rights for People with Dementia and their Carers in Scotland²⁹ adheres to the 'PANEL' principles. It was developed in partnership by the Scottish Parliament's Cross Party Group on Alzheimer's, the Scottish Human Rights Commission, Alzheimer Scotland, and was shaped by the views of over 500 people who took part in an extensive consultation process.

The Charter aims to empower people with dementia, people who support them and the community as a whole, to ensure their rights are recognised and respected and to ensure the highest quality of service provision to people with dementia and their carers. It has underpinned Scotland's subsequent Standards of Care for Dementia³⁰ and National Dementia Strategies³¹, which have also adopted the 'PANEL' approach.

To enable these human rights-based policies to be put into practice, 'Promoting Excellence: A framework for all health and social care staff working with people with dementia, their families and carers' has been developed. This details the knowledge and skills that will inform new ways of working for all health and social care services staff to ensure we enable people with dementia and their families and carers, to maximise their rights,

choices, and health and wellbeing at all stages of their unique dementia journey. The framework is designed to support transformation at a personal, service provider and organisational levels.

C-Change Scotland

C-Change Scotland is an organisation which provides support services for disabled people regardless of age and personal circumstances. They believe that we all need support at different times in our lives and with the right kind of support all of us can flourish and be full and active citizens.

C-Change Scotland provides individually tailored support for the people they work for, to enable them to achieve their goals and access their rights



on the same basis as all members of society. At the centre of their work is ensuring real choice for the people they work with. Whether recruiting the right support team or helping people to manage their money, they consider what the person wants and needs first, then design the support around this. They work in partnership with the person and/or their families, friends, advocates and allies to listen and learn, changing and evolving their support so that it suits where the person is now and is focused on where they want to go next in life.

Support plans are flexible and continuously assessed so that they are always guided by the individual's wishes. This empowers individuals to lead the lives they wish to without having to be restricted to rigid time slots and dictated support. At an organisational level, C-Change Scotland actively involves the people it works with in continuous review of its services to improve or redesign them. An Improvement Council, made up solely of service users, identifies issues, discusses them and makes suggestions for changes they would like to see, which are then directly passed on to the Board of Directors.

Find out more about C-Change Scotland and five other case studies of how human rights can be put in to practice on the SNAP Health and Social Care Action Group website³².

Rights for Life Declaration and Change Agenda

The Rights for Life³³ Declaration is a statement of the rights that people affected by mental health

issues in Scotland are calling for. Its aim is to help achieve transformational change to the way people affected by mental health issues enjoy their rights. The Rights for Life Change Agenda accompanies the Declaration.

It is intended to generate action to deliver the progressive realisation of the rights of people with mental health issues in Scotland today.

The Rights for Life Declaration and Change Agenda are based on the views of hundreds of people with experience of mental health issues and those family and friends who care for them. They started to take shape at a landmark two-day event on human rights and recovery held simultaneously online and in Glasgow during June 2015. Hundreds of delegates and over 60 guest speakers took part in panel discussions, showcases and debates, covering a vast array of topics. After this, widespread consultations on early drafts were held regionally, nationally and online. At this time, members of the Rights for Life Steering Group included Mental Health Network (Greater Glasgow), the Scottish Human Rights Commission, Scottish Independent Advocacy Alliance, Scottish Recovery Network, See Me and Voices Of eXperience.

By affirming human rights and detailing practical measures to achieve them, the Rights for Life Declaration and Agenda are intended to achieve real and lasting change to the lives of people affected by mental health conditions.



Conclusion

Although rights are often associated with courts and lawyers, they are also important standards that can pragmatically help to shape policy, programmes and interventions, including in health and social care.

Human rights provide a unifying language and philosophy to support cross-sectoral working and a joined up approach across health, social care, community empowerment, social security, housing, employment, education and independent living, as well as wider sectors.

Human rights and the rights-based approach can be embedded at all stages: policy and law; budgeting; implementation; monitoring, evaluation and review. To make a real difference, more needs to be done to increase awareness and understanding of how such approaches can be operationalised and help bridge the unacceptable and often wide gaps that continue to exist in Scotland between policy and strategies on the one hand, and people's daily experiences of their rights on the other.

While the current political and financial environment is challenging, now is a good time to explore how to develop new tactics that can respond to the present circumstances on a fair, robust and legal basis. A human rights-based approach to decision-making can be a very useful framework to inform difficult decisions and budget

prioritisation, by giving a structure and tools against which to balance competing needs and develop new and sustainable approaches to health and social care.

'The global economic crisis has presented a significant challenge to human rights protection in the UK. Yet, human rights should assist in responses to the economic crisis too, offering an objective framework for fair decision-making on the prioritisation of resources.'

Getting it Right?³⁴

The ALLIANCE welcomed the First Minister's announcements in 2016 that the Scottish Government is committed to working with civic Scotland to develop social and economic rights for all³⁵ and aims to "do even more and be even better at incorporating human rights in Scotland"³⁶. While we currently have a direct route to enforcing the European Convention on Human Rights through our domestic legal system, other international human rights are not yet part of (or 'incorporated' into) Scotland's laws, despite inclusion in binding international commitments made by the UK that apply to Scotland. This includes treaties like the International Covenant on Economic, Social and Cultural Rights and

the UN Convention on the Rights of Persons with Disabilities, which protect fundamental rights to health, education, employment, social security and an adequate standard of living, amongst others.

Incorporating social and economic rights into domestic law, policy and practice would support the realisation of a healthier and fairer Scotland.

As we grapple with significant socio-economic and geo-political challenges, the ALLIANCE will continue to urge the Scottish Government and other public bodies to use national initiatives in areas like health and social care, social security and community empowerment to progress the realisation of international human rights without waiting for legislative incorporation.





About the ALLIANCE

The ALLIANCE is the national third sector intermediary for a range of health and social care organisations. The ALLIANCE has over 1,800 members³⁷ including large, national support providers as well as small, local volunteer-led groups and people who are disabled, living with long term conditions or providing unpaid care.

Many NHS Boards are associate members³⁸ and many health and social care professionals are Professional Associates. Commercial organisations may also become Corporate Associates.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims. We seek to:

- Ensure people are at the centre; that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.

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