

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

Human rights are the basic rights and freedoms that belong to every person in the world. Based on a number of core principles such as dignity, fairness, equality, respect and autonomy, human rights protect our freedoms to control our own lives. They therefore enable us all to take part effectively in decisions made by public authorities which impact on our rights and to get fair and equal services from public authorities.



Taken together with Britain's well developed Equalities legislation – and more particularly the requirements of the General 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 each and every interaction. The transformation required is to move from a mindset of not breaching a person's human rights or not discriminating against them, to

a position where equality and human rights inform decisions about how to advance disabled people and people with long term conditions' social, economic and civic participation, as active participants and not just as passive "units of care."

The EHRC's own work in this area has uncovered some shocking abuses of equality and human rights in social care in England. The challenge now is to move beyond the poor practice we have uncovered and start designing support that is based around the consumers' needs, and not just that of the system.

With this in mind, I welcome the ALLIANCE's commitment to shaping this agenda through the compilation of this comprehensive thinkpiece which comes at a time when human rights in health and social care are in sharp focus. The upcoming legislation around health and social care integration provides an opportunity for Scotland to review progress and move towards a rights-led approach that can be translated into positive outcomes for disabled people and people who live with long term conditions.

**Alastair Pringle, Scotland Director,
Equality and Human Rights Commission**

Introduction

On International Human Rights Day, 10 December, this year the Scottish Human Rights Commission will launch “Scotland’s National Action Plan for Human Rights” (SNAP). Its publication will coincide with the Scottish Parliament debating legislation to integrate health and social care, representing another significant stage of policy development alongside self-directed support and the Healthcare Quality Strategy.

These developments come within the wider context of a public service reform agenda that emphasises greater involvement of individuals and communities in responding to societal challenges and needs. The Scottish Human Rights Commission, which is leading the development of SNAP, has identified ‘significant opportunities for synergy between the principles of public reform recommended by the Christie Commission and a human rights based approach’¹.

The difficult financial climate has given greater impetus to this drive to redesign services and develop new approaches. While statutory and third sector organisations are feeling the impact of budget cuts, individuals across Scotland are acutely impacted by reductions in support and services, increased difficulty finding sustained employment and substantial cuts to welfare

benefits. These same individuals are being characterised daily in the media as ‘scroungers’; a view that could not be in sharper contrast to the reality for the many people our members represent.

Many disabled people and people who live with long term conditions strive incredibly hard to overcome societal barriers and make a significant contribution to their families, communities and the Scottish economy. This is becoming even harder for many as the support that enables them to self manage and enjoy independent living is reduced. Indeed the UK Joint Committee on Human Rights last year warned that the right of disabled people to independent living could be severely undermined, stating that “the government and other interested parties should immediately assess the need for, and feasibility of, legislation to establish independent living as a freestanding right”.

This then is a crucial time for human rights in Scotland, both in providing a fundamental principled basis for health and social care policy and to ensure that progress towards equality and independent living continues at a time when it is at risk of being undermined.

The Scottish Human Rights Commission suggests that ‘strong human rights based legal and policy

frameworks must be translated into more consistent, positive outcomes to which individuals are entitled². This should be a key aim of health and social care integration and reinforces the call made by the ALLIANCE and many other third sector organisations³ for human rights to be reflected on the face of the legislation and in duties on Health and Social Care Partnerships.

In this short paper we explore human rights in the context of health and social care. We hope it will help to stimulate discussion and add to the existing body of work on this agenda. Most notably we would highlight the significant work done by the Independent Living Movement who have led, and continue to lead, much of this discourse. Human rights have also been a key tenet of the mental health user movement and of both the learning disability and dementia agendas. We draw upon the May 2012 paper 'Personalisation and Human Rights' by Kavita Chetty, John Dalrymple and Henry Simmons and on the discussion paper published by the ALLIANCE and partners '12 Propositions for Social Care' (authored by Dr Jim McCormick).



Recent History of Human Rights in the UK

1948 – Universal Declaration of Human Rights agreed by the General Assembly of the United Nations. This gave ‘all members of the human family’ entitlement to a set of rights, regardless of where in the world they live.

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

1966 – The United Nations General Assembly adopted two legally binding International Covenants on the rights contained in the Universal Declaration. The International Covenant on Economic, Social and Cultural Rights includes rights such as to the highest attainable standard of health and an adequate standard of living.

1966 – The International Covenant on Civil and Political Rights includes rights such as to life, to participate in public life. The UK has been legally bound by both Covenants since 1976.

1989 – The United Nations adopted the Convention on the Rights of the Child, to which the UK has been bound since 1991. This Convention provides for a range of rights, including the right to have a say in decisions and specific rights for disabled children. The Scottish Government is due to bring forward legislation this year to ensure the Convention is put into practice across public policy and services.

1998 – UK Human Rights Act passed, allowing the European Convention on Human Rights to be brought into domestic court cases. This act also aimed to bring about a cultural shift towards respect for human rights, including placing them at the heart of public services.

2006 – United Nations Convention on the Rights of Persons with Disabilities came into force (UK has been legally bound since 2009), reaffirming the human rights of disabled people and requiring governments to act to remove barriers to these. The Convention includes the right to live independently and be included in the community.

{The Universal Declaration of Human Rights and the two International Covenants above, are often collectively termed the ‘International Bill of Human Rights’.

How and why put human rights at the heart of health and social care in Scotland?

An Inclusive Society

UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

Article 19 – Living independently and being included in the community

...recognise the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

INTERNATIONAL COVENANT ON ECONOMIC, SOCIAL AND CULTURAL RIGHTS

Article 6

... recognise the right to work, which includes the right of everyone to the opportunity to gain his living by work which he freely chooses or accepts...

Article 11

... recognise the right of everyone to an adequate standard of living for himself and his family, including adequate food, clothing and housing, and to the continuous improvement of living conditions.

Article 12

...recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

Human rights provide the unassailable principle that people should be equal and free to participate in society as full and active members of society. Health and social care support provide one tool, among others, to ensure disabled people and people with long term conditions can do this; living their life the way they choose, at home, at work and in the community. Without it, many people cannot enjoy the human rights to which they are entitled⁴.

‘Without practical assistance, an accommodating physical environment and a receptive and inclusive culture, many disabled people cannot exercise their full and equal contribution in society; live free from discrimination and harassment nor contribute to a wealthier and fairer, healthier, safer and stronger, smarter and greener Scotland.’

Our Shared Vision for Independent Living in Scotland⁵

Access to independent living is a critical tool to enable people to contribute as citizens, creating an inclusive and equal society. Supporting independent living is to support not just individual rights, but to value the qualities that disabled people and people who live with long term conditions have to offer.

There are clear economic reasons too to promote,

develop and protect the right to independent living. For example, supporting disabled people to remain in work has economic benefits and supporting people to stay at home is more cost-effective than residential care. In 2011 the Scottish Association for Mental Health (SAMH) estimated that the cost to the economy in terms of ‘output losses’ resulting from the adverse impact of mental health problems on work and employment stood at around 3.2 billion pounds each year⁶.

Welfare reforms and tightening eligibility criteria for social care support are threatening to erode the support many people need to enable their full participation. If people are pushed to receiving only ‘life and limb’ support we will see unacceptable costs to individuals and to our society as the voice, value and contribution of many of our citizens is severely diminished. As public services struggle to reform to meet increasing need with smaller financial resource, human rights offers a fair and consistent basis to guide policy development, service redesign and resourcing decisions. This requires human rights principles to be embedded clearly within law and policy – for example the health and social care integration legislation – and within processes and decision making, including local strategic commissioning. It also requires far greater understanding of human rights across Scottish society.

'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, SHRC 2013

'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...

...A rights based approach can help to clarify expectations of fair, consistent and respectful experiences and of redress when standards fall below this. It offers a coherent values base to reform social care in order to "empower citizens and unlock them from the failings of past systems, rather than locking them into a new system that lacks a clear vision" (Chetty et al).'

12 Propositions for Social Care⁷

Adopting a human rights based approach should be closely aligned with the drive in Scotland for

greater co-production. This strongly reflects the human rights principles of participation, accountability, non-discrimination and empowerment.



Better experiences for people using health and social care and for staff

In Scotland there is a drive to improve not just outcomes but the experiences of people who use health and social care services, and those who provide it*. This is reflected in the Healthcare Quality Strategy and particularly in the new National Person Centred Health and Care Programme. Human rights based approaches can provide the basis for safeguarding quality (as in the National Care Standards, due to be reviewed shortly) as well as a tool to change the culture of services towards one that supports person centred

approaches, co-production, self management and asset-based approaches. This shift in approach has been shown to positively impact upon the experiences of people using, and delivering, services.

Embedding human rights in policy and legislation is crucial. However, to make a real difference much more needs to be done to increase understanding – particularly among those using and delivering services – of how such an approach can be used in practice. The

Case Study – The State Hospital, Carstairs, Lanarkshire

The State Hospital, located in Lanarkshire, is the high security forensic mental health hospital for Scotland and Northern Ireland. It provides psychiatric care in conditions of high security, for people with mental illness who are compulsorily detained under mental health or criminal law.

Putting human rights at the centre of policies and practices can be successful in achieving a transformational cultural change. After a critical report by the Mental Welfare Commission in 2000, the State Hospital conducted a fundamental examination of its human rights practice. A decision was taken to use the Human Rights Act as a vehicle for cultural change, to put the human rights of everyone – staff, patients, carers and family members – at the heart of The State Hospital's services.

The Scottish Human Rights Commission's (SHRC) 2009 independent evaluation, "Human Rights in a Health Care Setting: Making it Work" highlighted how this prompted The State Hospital to move from being an institution where rights were largely "left at the door", towards a more positive and constructive atmosphere with mutual respect between staff and patients. It found that increased participation of patients in decision-making had resulted in better staff and patient engagement, increased work-related satisfaction amongst staff, and increased satisfaction amongst patients over their care and treatment.

* It should be noted that these are not mutually exclusive groups – many people who use services also provide a wealth of support whether as paid staff, unpaid carers or through peer support or volunteer roles.

Scottish Human Rights Commission has made this point in relation to a range of key health and social care policy and legislation, including the National Care Standards and integration of health and social care.

We should not leave individuals alone to be responsible for asserting their own human rights, without support from a wider societal and structural embedding of

human rights knowledge and understanding.

Rights based approaches like Care about Rights⁸ need to become the norm, allowing for a shift in the balance of power that results in equal partnership between professionals and users and improved outcomes and experiences for us all.

Case Study – Care about Rights

Care about Rights 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 workers to involve service users, their families or their advocates in decision-making and deliver more personalised services, thus helping to shift the balance of power relationships between providers and users.

The Care about Rights resources look at:

- What human rights are and how they are applicable in 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 using services, their families and others.

Around 1,000 care staff and managers have taken part in training for Care about Rights since September 2010, as well as around 80 older people and older people's advocates across Scotland.

More than half of care staff respondents to the follow up survey on Care about Rights felt that it was helping them to deliver better person centred care, whilst also helping older people and their representatives to articulate concerns and provide a framework for change. Care plans had been enhanced, even if the agreed approach did not change significantly, and the satisfaction of both care users and the workforce increased. The evaluation included a recommendation that using person centred, human rights based approaches becomes a core competence for the care workforce.



Bridging the cultural divide between health and social care

Personalisation is no longer only the domain of social work and social care. The Government's NHS Quality Strategy has person-centred care as a main theme and there is a clear desire to ensure that personalisation of health care evolves from this. The integration agenda offers a unique opportunity to merge this thinking around clear values and principles...

...The legal underpinning of human rights seeks to ensure that in practice we are all able to live the lives we choose to live, and participate equally in the communities in which we live, regardless of our status in society.

Human rights based and person centred approaches therefore share the same starting point - the personal experiences of the individual - and the same end goal - empowering individuals to fulfil their potential by giving them the authority, capacities, capabilities and access needed to change their own lives, improve their own communities and influence their own futures.

Furthermore, building on these legal obligations, a human rights based approach to the development, design and delivery of services means putting human rights considerations, and therefore the participation of the individual, at the centre of all policies and practices.

Personalisation and Human Rights⁹

Human rights and independent living provide a framework for driving and connecting a greater shared understanding between health and social care professionals. However, as noted by Chetty et al¹⁰, it can still be argued 'that our current health and social care system lacks explicit guiding principles.' It has also been argued that progress to embed human rights has been reflected to a greater degree within health services than in social care (for example through the Patients' Rights Act), although many would also argue that the human rights based understanding of independent living is far stronger within social care than the NHS.

'Human rights, independent living and citizenship provide a framework for driving and connecting key agendas across health, social care and more widely, and as a basis for developing truly integrated policy, support and services nationally and locally.'

Integration of Adult Health and Social Care in Scotland: Consultation; a Shared Statement from Third Sector Organisations (ALLIANCE and partners 2012)

In responding to the Scottish Government's recent consultation on the integration of health and social care, many organisations highlighted

concerns about the cultural differences between health (with its medical model) and social care (with its basis in a social model approach). In practice this has significant implications, particularly if a medical model is allowed to dominate, putting at risk the

focus on independent living, citizenship and empowerment. Human rights offers a strong, effective shared basis to help bring together health and social care and overcome cultural barriers to joined up, effective support.

Case Study – A Human Rights Based Approach to Dementia

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 involvement of people living with dementia and their carers.

Scotland's National Dementia Strategy (2010) is founded in human rights, based on the 'PANEL' approach which the Scottish Human Rights Commission has promoted and which is endorsed by the United Nations, which emphasises the rights of everyone to:

- **P**articipate in decisions which affect their human rights
- **A**ccountability of those responsible for the respect, protection and fulfilment of human rights
- **N**on-discrimination and equality
- **E**mpowerment to know their rights and how to claim them
- **L**egality in all decisions through an explicit link with human rights legal standards in all processes and outcome measurements

The Strategy is built on The Charter of Rights for People with Dementia and their Carers in Scotland, which aims to empower people with dementia, those 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. Its development reflected the views of over 500 people who took part in the widespread consultation carried out on behalf of the Cross- Party Group by Alzheimer Scotland.

To enable the human rights based National Dementia Strategy to be put into practice a framework – Promoting Excellence: A framework for all health and social care staff working with people with dementia, their families and carer¹¹ – has been developed. This is also underpinned by the charter of rights, and '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 level.



Tackling Health Inequalities

International Covenant on Economic, Social and Cultural Rights

Article 12 (part 1)

...recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

The adoption of human rights based approaches offers new perspectives and solutions in a number of policy areas. Audit Scotland's recent report into health inequalities stated that overall health in Scotland had improved in the past 50 years, but there are still deep-seated inequalities. These are largely a result of deprivation, although age, gender and ethnicity were also factors. Health inequalities are widely acknowledged as one of the most ingrained public policy issues in Scotland.

The adoption of a human rights based approach to health will be critical if we are to address Scotland's growing health inequalities. This should involve the development of policies and programmes consistent with human rights, which allow for redress for victims of violation to the right to health. It must also enable active citizenship with individuals involved in mutual approaches to tackling health inequalities and promoting good health.

'Barriers to realising human rights drive and deepen experiences of poverty and in turn social exclusion'

Scottish Human Rights Commission, 2012

Income poverty is undoubtedly a significant factor in our entrenched health inequalities. Disabled people and people living with long term conditions are far more likely to be living in poverty, experience debt and be unemployed or in low paid, less secure employment.^{12 13} This significant inequality is being further compounded by welfare reforms, a rising cost of living, an increasingly competitive labour market and reductions in support and services.

- Just under half of disabled people in Scotland are in paid employment compared to around 75% of the general population¹⁴
- Young disabled people aged 16 are twice as likely not to be in any form of education, employment or training (NEET) as their non-disabled peers. This increases to three times as likely by the age of 19¹⁵
- Disabled people are more than twice as likely as non-disabled people to have no qualifications¹⁶

International rights based approaches to poverty have been successful in shifting the emphasis from needs to socially and legally guaranteed entitlements¹⁷. Both wealthy and low-income

countries have used rights-based approaches to poverty in order to:

- Reframe conceptions of poverty and challenge stereotypes of people affected by it
- Mobilise alliances between disparate groups around anti-poverty goals
- Where appropriate, to hold Governments accountable for poverty inside and outside the courtroom

United Nations Convention on the Rights of Persons with Disabilities

Article 25 – Health

...recognise that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability...

Health inequalities also stray beyond poverty and economic challenges. For instance, healthcare services in Scotland face a major challenge in ensuring that accessible information is provided for people who have communication support needs. A lack of accessible information can prevent people from accessing healthcare services, for example:

- RNIB¹⁸ have raised concerns about poor, ineffective communication between healthcare staff and people with a sensory impairment.
- This can result in significant adverse impact upon care, leading to missed appointments,

poor compliance with treatment, inappropriate use of medicines and poor satisfaction amongst service users.

- The Same as You? 2000-2012: Consultation Report¹⁹ identified gaps in provision and recommended 'primary care services should provide accessible health information for people with learning disabilities' as a future priority.

United Nations Convention on the Rights of Persons with Disabilities

Article 21 – Freedom of expression and opinion, and access to information

[right to information in] accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost... accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice [by disabled people]'

In Scotland there is a renewed focus on health inequalities, through the work of the Ministerial Task Force on Health Inequalities and an inquiry expected to be undertaken this year by the Scottish Parliament Health and Sport Committee. Human rights needs to feature more strongly in debates on health inequalities and form part of the basis for an approach to tackling this deeply entrenched inequality in Scottish society.

Conclusions

This short paper seeks to contribute to the discussion on human rights in Scotland, particularly as they apply to health and social care. It is one part of the ALLIANCE’s work in this area and we look forward to building on it with our members and partners throughout 2013.

Human rights principles run through many current themes within health and social care. Independent living and self-directed support are explicitly founded on human rights, while person centred care, self management and co-production strongly reflect key elements of a human rights approach.

The ALLIANCE would echo the Scottish Human Rights Commission’s call for a more explicit linkage between the public service reform agenda and human rights. The SHRC asserts that this would ‘ensure the empowering potential of human rights for the population – to act as rights holders not service users in prioritising and shaping interventions. It would also add an objective and enforceable legal basis to ensure positive outcomes in terms of human rights.’

Human rights need to feature much more strongly across our public discourse on health and social care, and beyond. This requires work to build better understanding, including of how human rights can be applied in every day life and how they can offer a tool to help drive improvement and culture change in health and social care.

There is also a critical need to tackle the negative

Public Service Reform and Human Rights principles aligned (Scottish Human Rights Commission 2012)

Christie Commission principles	Human rights based approach PANEL principles
Increased participation	Participation: everyone has a right to take part in decisions which affect their human rights
Accountability; integration of services	Accountability: indicators, monitoring, access to justice state responsibility and the need for joined up approach to realisation
Reduction of inequalities; prioritisation of vulnerable and disadvantaged people	Non-discrimination and the pursuit of equality and the prioritisation of the most marginalised
	Empowerment of people to know and claim their rights
Outcome focus; transparency; preventative spending	Legality: duties to respect, protect and fulfil all human rights (including prevention, protection and remedy duties)

public attitudes that often undermine independent living and citizenship for disabled people and people with long term conditions, particularly in the context of welfare reform. In its 2011 report ‘Hidden in Plain Sight’ the Equality and Human Rights Commission (EHRC) reports widespread harassment of disabled people in Scotland and cites a lack of action by public authorities to tackle this.

As we grapple with significant socio-economic challenges human rights can offer a robust common framework to support fair and effective policy, practice and services and help steer our collective efforts towards good health, well-being and quality of life for all of Scotland’s citizens.

About the ALLIANCE

The ALLIANCE is the national third sector intermediary for a range of health and social care organisations. The ALLIANCE has over 270 members including a large network of national and local third sector organisations, associates in the statutory and private sectors and individuals. Many NHS Boards and Community Health and Care Partnerships are associate members. Many of the ALLIANCE's members proactively promote human rights and adopt human rights based approaches within their own work and services.

The ALLIANCE's 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 works towards its vision in three main ways; 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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