

The Scottish Human Rights Commission

A Consultation on proposals for National Health and Wellbeing Outcomes relating to the Public Bodies (Joint Working)(Scotland) Act 2014

Response to Scottish Government Consultation

July 2014

The Scottish Human Rights Commission is a statutory body created by the Scottish Commission for Human Rights Act 2006. The Commission is a national human rights institution (NHRI) and is accredited with 'A' status by the International Co-ordinating Committee of NHRIs at the United Nations. The Commission is the Chair of the European Network of NHRIs. The Commission has general functions, including promoting human rights in Scotland, in particular to encourage best practice; monitoring of law, policies and practice; conducting inquiries into the policies and practices of Scottish public authorities; intervening in civil proceedings and providing guidance, information and education.

The Commission welcomes the Public Bodies (Joint Working) (Scotland) Act 2014 (the "Act") and the Health and Wellbeing Outcomes as a means of improving the quality and consistency of health and social care services, ensuring they better align with a human rights based approach. Human rights principles and standards align with the core central objectives of health and social care integration, providing both a legal and value base for the delivery of person-centred care.

The Commission welcomes the policy focus of integration on ensuring better person-centred outcomes for all. These shared nationally agreed Outcomes provide an opportunity to ensure human rights measures and indicators are built into the joint objectives of the integration authority. It is understood that this will also be followed through into the work of the Social Care Social Work Improvement Scotland (Care Inspectorate) and Healthcare Improvement Scotland and reflected in Single Outcome Agreements.

The Commission considers the National Health and Wellbeing Outcomes as of critical importance in ensuring that the integration agenda remains focused on the cultural shift required within health and social care from a focus on needs to a focus on rights. They can also help address the challenge of integrating the differing cultures of the medical and social care professions to ensure that both are centred around people rather than systems. An effective cultural shift will help to achieve better outcomes for people, as opposed to only the structural changes that require to be put in place.

In order to ensure that the desired cultural change takes place, there should be consistency in the approach taken, from the primary legislation, through the subordinate legislation and into the guidance surrounding the Act. The Commission

considers that reflecting a human rights based approach throughout these steps would ensure that the vision is translated from theory into practice. This is essential to address the findings of the research underlying SNAP, that while Scotland has many examples of good human rights based laws and some rights based policy, there remain reports of divergent practice for those affected¹.

There has been a strong call for a human rights based approach to health and social care integration from people who access services, unpaid carers and the third sector². The use of a human rights based approach also helps connect key agendas across health, social care and more widely, such as Self Directed Support.

An approach to ensuring outcomes are aligned with human rights is consistent with the Scottish Government's commitments as outlined in Scotland's National Action Plan for Human Rights (SNAP)³, launched in December 2013. SNAP is a collaborative plan, developed by a range of bodies including NHS Health Scotland, Scottish Government, Convention of Scottish Local Authorities and the Care Inspectorate. Priority 4 of SNAP is to enhance respect, protection and fulfilment of human rights to achieve high quality health and social care. The alignment of the Outcomes with human rights will assist in the achievement of this objective.

Getting it Right⁴ highlighted that action was needed in order to assure and not assume the implementation of human rights at the level of service delivery and practice. With regard to the National Health and Wellbeing Outcomes, this means having rights based outcomes which are consciously linked to human rights and have regard to the full range of internationally recognised human rights. They must be supported by clear guidance and training on the practicalities of implementing this approach. The Commission notes that the Health and Wellbeing Outcomes will be read alongside the Integration Planning and Delivery Principles, which include requirements relating to human rights standards, such as to "respect the rights of service-users" and to "take account of the dignity of service-users". In order to reflect and bolster these principles, human rights standards should be carried through into the wording of the Outcomes.

A human rights based approach assists in achieving multiple, complementary, aims. It helps fulfil the legal duty on all public bodies or those performing a public function to comply with the Human Rights Act 1998 (s.6). In addition, it will also help drive up standards and ensure that a person-centred approach is taken, putting the individual patient or service user at the centre of policy, planning and delivery.

¹ 'Getting it Right? Human Rights in Scotland' SHRC 2012
<http://www.scottishhumanrights.com/application/resources/documents/SNAP/GettingitRightAnOverviewofHumanRightsinScotland2012.pdf>

² 'Being Human, A Human Rights Based Approach to Health and Social Care in Scotland', ALLIANCE 2013, 'It's our world too: 5 asks for a better Public Bodies (Joint Working) (Scotland) Bill' ILiS and Inclusion Scotland, August 2013

³ SNAP- <http://www.scottishhumanrights.com/actionplan/snap>

⁴ Ibid at footnote 1

A series of independent evaluations⁵ have shown that a human rights based approach has a number of benefits to delivering effective services. It:

- **Is “person-centred”**: It puts people at the heart of effective public service design and delivery in a consistent and clear way. It provides a legal and objective basis for ensuring a person-centred approach in practice, focusing the attention of service design on what will deliver the best outcomes for people, rather than one-size-fits all policies which seek to make people fit systems.
- **Is better for everyone**: It reflects the rights of everyone involved, not only “service users” but also public and private sector workers, individuals and groups. Taking a human rights based approach means considering the rights of all of those involved. It has for example been found to increase work related satisfaction of staff and improvements in services for those who use them.
- **Helps good decision-making**: It helps to balance rights and risks, getting the balance right between protecting people from risk of harm and upholding autonomy. Understanding the balance of these rights and duties provides a framework for making difficult decisions on balancing risk and rights.
- **Helps improve institutional culture**: It helps to reinvigorate a public service ethos among staff, enhancing accountability of organisations in shaping policy and decision making through transparency and the participation of communities. As a values-based framework with the force of law, human rights helps reinforce the purpose of public service - to improve people’s lives.
- **Improves relationships**: It helps improve relationships between those who deliver and those who use public services. Participation in decision making helps enhance legitimacy and ownership. It has for example been found to help public services move from “them and us” to a more constructive atmosphere based on mutual respect, leading to a reduction in complaints.
- **Ensures legal compliance and promotes best practice**: It ensures compliance with human rights law and provides a foundation for other duties including in equality, freedom of information and data protection.

The Commission understands that guidance regarding the Outcomes will be drafted and consulted on in due course. In order to ensure that the National Health and Wellbeing Outcomes will be understood by users of services, as well as those planning and delivering them, it is essential that the guidance explains in detail the concepts expressed in the Outcomes in a way which makes them practical and meaningful. The guidance should explain what it means to take a human rights based approach, using the PANEL principles and the FAIR framework (as included in the Statutory Guidance to accompany the Social Care (Self-directed Support) (Scotland) Act 2013) and how to apply those in practice. The PANEL approach has already been integrated into the Dementia Strategy and Learning Disability Strategy, and is the model proposed in the National Care Standards Review currently under consultation. Incorporating this approach in relation to the Outcomes offers an

⁵ See for example, GEN, The University of Bedfordshire and Queen Margaret University, Evaluation of Care about Rights, Phase 2 report to the Scottish Human Rights Commission, October 2011; Scottish Human Rights Commission, Human Rights in a Healthcare Setting: making it work, an evaluation of a Human Rights Based Approach at The State Hospital, December 2009

opportunity for a consistent approach based on strong core principles to be echoed across related policy areas.

Rights based outcomes

Rights based outcomes should generally accord closely with the framework for protecting and promoting human rights in Scotland - that is, the Human Rights Act 1998, together with other regional and international human rights instruments that the UK has signed up to (such as the European Convention on Human Rights, the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention on the Rights of the Child, the Convention Against Torture and the Convention on the Rights of Persons with Disabilities). The Scotland Act 1998 specifically devolves the observation and implementation of international obligations, which will include these international treaty obligations.⁶ The HRA 1998 establishes human rights as an overarching framework in terms of which all legislation must be read⁷, in light of which, the Act and its Regulations must be read through a human rights lens. Referencing human rights in subordinate legislation, such as the Outcomes, merely highlights this duty, as a means of embedding a human rights based approach and effecting culture change. It is clear that all of the Outcomes have a grounding in human rights law and practice. As such, human rights should be considered an element of each and every Outcome.

Outcome 1: People are able to look after and improve their own health and wellbeing and live in good health for longer.

There is an obligation on States to fulfil the right to health⁸ and create an enabling environment for its realisation. One of the underlying determinants of the right to health is access to health-related education and information.

It is recommended that the language used in Outcomes 6 and 8 may be reflected here where individuals and communities are “*supported* and able to look after and improve their own health and wellbeing.” This better reflects the positive duties on the authorities under human rights law.

Recommended wording: People are supported and able to look after and improve their own health and wellbeing and live in good health for longer.

⁶ Scotland Act 1998, Schedule 5, s7(2)

⁷ HRA 1998, s.3

⁸ International Covenant on Economic, Social and Cultural Rights: art.12, The International Convention on the Elimination of All Forms of Racial Discrimination 1965: art. 5 (e) (iv); The Convention on the Elimination of All Forms of Discrimination against Women 1979: arts. 11 (1) (f), 12 and 14 (2) (b); The Convention on the Rights of the Child 1989: art. 24; The International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families 1990: arts. 28, 43 (e) and 45 (c); The Convention on the Rights of Persons with Disabilities 2006: art. 25. Important characteristics of the right to health are clarified in general comment N° 14 (2000) on the right to health, adopted by the Committee on Economic, Social and Cultural Rights.

Outcome 2: People, including those with disabilities, long term conditions, or who are frail, are able to live, as far as reasonably practicable, independently and at home or in a homely setting in their community.

It is welcome that the concept of independent living, enshrined in Article 19 of the UN Convention on the Rights of Persons with Disabilities (UNCPRD) forms the basis of an Outcome. However, the full range of protection given by Article 19 UNCPRD is not explicitly provided for here. Article 19 requires that disabled people have “the equal right...to live in the community, with choices equal to others”. The inclusion of the phrase “as far as reasonably practicable” does not reflect the essential element of autonomy and choice for the individual with regard to their living arrangements. It suggests that restrictions may be placed on this right by the state where it is not considered “practicable” that it be facilitated. Conversely, Article 19 may be seen to include both immediate obligations and obligations to be fully achieved (progressively) over time. As such, the current wording risks leading to practice which falls short of the spirit of the UNCPRD.

The definition of independent living adopted by ILiS, which has been developed by disabled people and has already been adopted by the Scottish Government, CoSLA and the NHS as equal partners of the ‘Independent Living Programme’⁹, is as follows:

Independent Living means “disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work and in the community. It does not mean living by yourself or fending for yourself. It **means rights to practical assistance and support to participate in society and live an ordinary life**”¹⁰.

This definition more fully describes the right enshrined in Article 19 and the ethos behind it. It also highlights that the concept of independent living embodies more than living in one’s own home or in a homely setting. In order to capture the full range of rights within the concept of independent living, the Outcome could read “...are able to live *as independently as possible in the community, with choice, dignity and control*”. This wording still allows for situations where it is not, in fact, possible for individuals to live in the community, for example, by reason of their properly authorised detention.

Recommended wording: People, including those with disabilities, long term conditions, or who are frail, are able to live as independently as possible in the community, with choice, dignity and control.

Outcome 3: People who use health and social care services have positive experiences of those services, and have their dignity respected.

The Commission welcomes the inclusion of the concept of “dignity”, which reflects the right to a private and family life enshrined in Article 8 ECHR. An all-encompassing rights based approach to health and social care services would

⁹ See the signed shared vision on independent living here: <http://www.scotland.gov.uk/Publications/2010/03/29164308/1>

¹⁰ ILiS (2009) “The Essential Guide to Independent Living”

reflect, amongst other rights, the right to health enshrined in Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR). The right includes, *inter alia*, that health services, goods and facilities must be provided to all without any discrimination (including health-related discrimination) and that all services, goods and facilities must be available, accessible (physically and financially), acceptable (medically and culturally) and of good quality (scientifically and medically appropriate). Many of these facets of the right to health are essential to a progressive health and social care system and should not be assumed but rather should be assured through outcome measures.

The wording should also reflect the participative role of individuals in shaping their own health and social care. The current wording could be interpreted as services doing something “to”, rather than “with” people. It is recommended that this Outcome is amended to reflect “*human rights*” as well as “dignity”, in order to reflect the full scope of the right to health. This would also encompass important core principles such as autonomy and participation.

Recommended wording: People who use health and social care services have positive experiences of those services, which uphold their dignity and human rights.

Outcome 4: Health and social care services are centred on helping to maintain or improve the quality of life of service users

AND

Outcome 5: Health and social care services contribute to reducing health inequalities

The Commission welcomes Outcomes based on continuous improvement and addressing inconsistencies in health and social care, which reflect the State’s obligation to progressively realise all economic and social rights, such as the right to health. Addressing health inequalities also reflects human rights obligations under positive obligations of the right to life (Article 2 ECHR) and the right to health¹¹.

Outcome 6: People who provide unpaid care are supported to reduce the potential impact of their caring role on their own health and wellbeing.

This Outcome is broadly consistent with the human right of carers to maintain a private home and family life under Article 8 of the ECHR, however, it is currently phrased in negative terms. The focus of the current wording, on reducing the impact of caring is on the caring role, rather than the broader life of the carer. Article 8 protects a number of aspects of a private and family life, including the right to maintain family and social relationships, which is an aspect of private life not explicitly included in the concept of “health and well-being”. It may be helpful therefore to explicitly reference the rights of carers in the Outcome.

¹¹ Ibid at footnote 6

Recommended wording: People who provide unpaid care are supported to improve their own health and wellbeing, including having a private and family life alongside caring.

Outcome 7: People who use health and social care services are safe from harm.

While keeping individuals safe from harm is protected in human rights law through the positive duties set out in Article 2 of the ECHR and the right to life, Article 3 and the prohibition on inhuman or degrading treatment and Article 8 and the right to a private and family life, it must also be balanced against the principles of autonomy and participation in decision-making, which are also enshrined as essential components of the right to a private and family life¹².

One of the findings of the Commission's Care about Rights project¹³ was that services were at times time risk-averse as they tried to protect patients and service users from harm, while overlooking the need for service user involvement, choice and control in decision-making. A rights based approach assures that people participate in decisions about their lives and that their rights are respected at all times, often balancing risks and quality of life. As one participant in the work stated, human rights *"helps us to look at the issue of proportionality in all that we do in terms of care provision and the balance of risk – a particular example would be around the use of locked doors in care homes."* The evaluation research following Care About Rights showed that 93% of respondents to the follow up survey reported that human rights have the potential to assist care workers in using a human rights approach to balance risk in decision-making.¹⁴ It is important therefore that the Outcome related to safety from harm is balanced against the full range of human rights considerations including autonomy and participation in decision making. The addition of human rights language could assist in reflecting the need for balance.

Recommended wording: People who use health and social care services are safe from harm and have their autonomy, dignity and human rights respected.

Outcome 8: People who work in health and social care services are supported to continuously improve the information, support, care and treatment they provide and feel engaged with the work they do.

An Outcome focusing on workforce development is welcomed as it will be essential to the delivery of the goals of integration. It is considered that a robust human rights underpinning to workforce development initiatives around integration will assist in the achievement of this Outcome. Independent evaluation evidence from the embedding

¹² *Pretty v United Kingdom* (2002) at para 61

¹³ Care About Rights <http://www.scottishhumanrights.com/careaboutrights>

¹⁴ Evaluation of Care About Rights, Phase 2: Report to the Scottish Human Rights Commission, GEN, The University of Bedfordshire and Queen Margaret University, October 2011-
<http://www.scottishhumanrights.com/careaboutrights/evaluation>

of a rights based approach in the workforce at The State Hospital¹⁵ and in the social care sector through the Commission's Care about Rights project has shown how, by adopting a human rights based approach, a more positive and constructive atmosphere, with mutual respect between staff and patients, was created. This led to increased staff and patient engagement, increased work-related satisfaction amongst staff and increased satisfaction amongst patients over their care and treatment. Staff also reported a reduction in stress and anxiety and increased understanding of how to make choices and take decisions in a rights respecting manner as well as the meaning and benefit of their own human rights.

The aspect of workers' own human rights is not currently reflected in the Outcome currently, which considers workers as duty bearers rather than rights holders. A robust human rights based outcome would also reflect all aspects of the right to work under ICESCR and the ILO Conventions.

Recommended wording: People who work in health and social care services are supported to continuously improve the information, support, care and treatment they provide, feel engaged with the work they do and have their rights respected.

Outcome 9: Resources are used effectively in the provision of health and social care services, without waste.

The policy aim behind this Outcome explains the benefits for both individuals and services in targeting resources effectively, however the Outcome itself focuses on whether resources are "wasted", rather than person-centred outcomes. This ethos should be reflected in the Outcome itself.

In addition, in human rights law, States have the obligation to progressively achieve the full realisation of all economic and social rights, to the maximum of their available resources¹⁶. This accords with the policy aim behind this Outcome and could be expressly reflected in the wording of the Outcome. While the concept of progressive realisation applies to all rights under the Covenant, some obligations are of immediate effect, in particular the undertaking to guarantee that all rights are exercised on the basis of non-discrimination and the obligation to take steps towards the realisation of the rights, including the right to health, which should be concrete, deliberate and targeted. Each of these aspects could be encompassed by reflecting the wording of international human rights standards in the Outcome itself.

Recommended wording: The maximum available resources are directed to achieve progressively the full realisation of these Outcomes.

¹⁵ Human Rights in a Health Care Setting: Making it Work An Evaluation of a human rights-based approach at The State Hospital-

<http://www.scottishhumanrights.com/application/resources/documents/HRHCSFINALVERSION.pdf>

¹⁶ Article 2 (1) of the International Covenant on Economic, Social and Cultural Rights