

Response to Consultation on proposals on the Integration of Adult Health and Social Care in Scotland

The Scottish Human Rights Commission

September 2012

The Scottish Human Rights Commission was established by The Scottish Commission for Human Rights Act 2006, and formed in 2008. The Commission is a public body and is entirely independent in the exercise of its functions. The Commission mandate is to promote and protect human rights for everyone in Scotland. The Commission is one of three national human rights institutions in the UK, along with the Northern Ireland Human Rights Commission and the Equality and Human Rights Commission.

Introduction

The Commission welcomes the intention of the proposals to improve outcomes through health and social care services which are integrated around the needs of individuals, their carers and family members. The proposals objectives to shift the balance of care from institutional care to services provided in the community and ensure resources follow people's needs are shared with proposals on Self – Directed support and the principles of the NHS Health Care Quality Strategy all of which are ultimately to ensure care is “person centred”. Human Rights principles and standards align with this core central objective providing both a legal and value base for the delivery of person centred care.

As well as a compliance duty on all public bodies or those performing a public function to comply with the Human Rights Act 1998 (s6), a human rights based approach to health and social care 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.

The value of a human rights based approach in both health and social care settings has been clearly evidenced by the independent evaluation reports of a human rights approach in practice at the State Hospital¹ and in the social care sector through the Commission's Care about Rights project.² In a social care context for older people the Care about Rights evaluation research demonstrated, for example, that following participation in human rights training ninety seven percent of those who completed the follow up survey agreed that more effective delivery of person-centred care and increased quality of life for service users were potential benefits of a human rights based approach.³

The Commission believes that for the proposals regarding integration to lead to the envisaged improvement in outcomes for people who require care and support that human rights should be built into the nationally agreed outcomes and outcome indicators or measurements to be established. Furthermore a human rights foundation ought to be explicit to the professional and workforce development

¹ <http://scottishhumanrights.com/application/resources/documents/HRHCSEFINALVERSION.pdf>

² <http://www.scottishhumanrights.com/careaboutrights>

³ 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>

that will be required to lead to the necessary cultural change to put the proposals into practice. We recognise that these recommendations may relate to wider improvement opportunities which will inevitably arise from the integrated approaches outlined in the proposals.

Legal framework

Relevant human rights instruments referred to in this submission include:

- Scotland Act 1998
- Human Rights Act 1998
- European Convention on Human Rights, particularly Articles 2, 3, & 8
- European Social Charter
- UN International Covenant on Civil and Political Rights
- UN International Covenant on Economic, Social and Cultural Rights, particularly Article 12
- UN Convention on Rights of Persons with Disabilities, particularly Article 19

Issues identified

Proposed Framework for Integration

The Commission wishes to comment on only certain aspects of the proposals which have the most relevance for the realisation of human rights in health and social care services.

National Outcomes for adult health and social care

The Commission welcomes the outcomes – led approach to reform that is proposed. It is understood that the nationally agreed outcomes will apply across adult health and social care, ensuring evidence and information is available to demonstrate progress in accordance with related indicators and measures. The Commission strongly believes that these shared nationally agreed outcomes to be delivered within an integrated budget provide the opportunity to ensure human rights measures and indicators are built into the joint objectives of the partnership. This should also be followed through into the work of the Care Inspectorate and Healthcare Improvement Scotland.

While the draft health and care integration outcomes outlined in the consultation proposals both align and reference human rights the full range of rights protection is not explicitly included in the 7 outcomes and there are significant gaps which should be addressed.

It is welcome that the concept of independent living, enshrined in Article 19 of the UN Convention on the Rights of Persons with Disabilities (UN CRPD) is explicitly mentioned as an outcome (outcome 2). The full range of protection given by Article 19 UN CPRD is not provided for here however. While outcome 2 provides for people living “as safely and independently as possible in the community” the protection afforded in Article 19 provides, *inter alia* for “access to a range of in-, 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.” The notions of safety and independence stated as outcomes here do not therefore fully reflect the need for support to encompass all aspects of an individuals well- being, personal physical and psychological integrity and social

inclusion⁴ which should equally be regarded as health and social care outcomes together with safety, independence and control.

It is also welcome that human rights are explicitly referenced in relation to keeping services safe and individuals guarded from harm (outcome 5). While this is protected in human rights law through the positive duties set out in Art 2 of the European Convention on Human Rights (ECHR) and the right to life, Article 3 and the prohibition on inhuman or degrading treatment and Art 8 and the right to a private, home and family life, there are further considerations of importance in ensuring individuals rights are respected, protected and fulfilled which must also be taken into consideration.

One of the findings of the Commission's Care about Rights project 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.⁵ It is important therefore that the outcome related to safe services and guarding from harm is balanced against the full range of human rights considerations including autonomy and participation in decision making.

In relation to the engaged workforce outcome, (outcome 6) as outlined in this submission, it is strongly recommended that human rights become integral to workforce development to ensure both support for staff in service delivery and improvement in outcomes. It will also be essential in order to support the integration proposals considered in this consultation to ensure both frontline workers and the professionals involved in the commissioning of services take a person centred approach and silo working practices are broken down.

Research carried out at the State hospital demonstrated 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.⁶

⁴ Also a protected aspect of Article 8 ECHR i.e Botta v. Italy, judgment of 24 February 1998, Reports 1998I, p. 422, § 33 Molka v Poland Application no. 56550/00; Evans v UK 2007, Grand Chamber, Pretty v UK (2002)- Article 8 as encompassing "the right to personal autonomy, personal development".

⁵ 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>

⁶ 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>

Consideration may also be given to further right to health measures as the basis for human rights based outcomes. The right to health is enshrined in Article 12 of the International Convention on Economic, Social and Cultural Rights (ICESCR)⁷ and 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. 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.

In terms of the related measurements and indicators that will underpin the delivery of the national outcomes the Human Rights Measurement Framework, commissioned by the EHRC and the Commission and developed by researchers at the Centre for Analysis of Social Exclusion at the LSE, with the British Institute of Human Rights, provides useful structural, process and outcome indicators on the right to health and a range of rights protected by the Human Rights Act.⁸ This provides a useful reference for the future development of measurement and indicators of progress towards the realisation of human rights.

Integrated budgets and resourcing

It is outlined that a key priority of the proposals is to improve outcomes by ending “cost- shunting” between the NHS and local authorities by integrating resources for adult services with joint accountability managed by the Jointly Accountable Officer on behalf of the Health and Social Care Partnership.

It is considered however, that for resources to truly “lose their identity” within the integrated budget and for individuals to be appropriately referred to the services that meet their needs that some cultural barriers will have to be overcome alongside the financial and accountability incentives and disincentives outlined in the proposals. Without the necessary shift in thinking there is potential for a culture of competing for scarce resources and silo working between service areas to persist in a way which is unhelpful to meeting the needs of the end user of services. Connecting with human rights values will assist in retaining a person centred and outcome based focus by all in managing resources across both health and social care. This will facilitate balanced decision making as resources shift from acute and institutional services to preventative, anticipatory and rehabilitative ones while safeguarding individuals rights and minimum and progressive standards across all services.

It is essential therefore that human rights are core to the nationally agreed outcomes and also to the underpinning ethos and value base of all health and social care professionals. This also should be assured and not assumed through explicit reference to human rights in both the outcomes and all workforce development and

⁷ The Right to Health is also recognised in a number of other international treaties including –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.

⁸ Human Rights Measurement Framework - <http://www.equalityhumanrights.com/human-rights/our-human-rights-work/human-rights-measurement-framework/>

education.

As proportionally less resources are directed towards institutional care and re-directed towards community provision it will also be essential that the appropriate safeguarding mechanisms are put in place to guard against individuals finding themselves in circumstances which could amount to a violation of their human rights. Supporting individuals to remain with family in their own homes for longer periods may have a positive impact on the private home and family life (Article 8 ECHR) of individuals and their right to live independently in the community (Article 19 UN CRPD). However, the rights of the individual to be protected from harm, neglect or social isolation in home settings must also be considered. In particular the right to life (Article 2 ECHR) and right not to be subject to inhuman or degrading treatment (Article 3 ECHR) may be engaged in the most extreme circumstances by the proposals where the increased number of vulnerable people being supported in their own homes is not accompanied by the appropriate protection and regulatory measures, including of the home care sector and of those providing services directly to the service user. Furthermore, the physical and psychological wellbeing of carers must also be considered where there is an increased reliance on their services without appropriate support and respite.

It is also noted that the proposals anticipate that “a more integrated approach to sharing information across services and local systems within appropriate boundaries, will be required to enable and evidence improvement.” Privacy concerns which engage Article 8 of the ECHR may also be raised here and should be given further consideration.

Finally, in relation to integrated budgets and resourcing, it is noted that it is intended that “to support the most effective use of resources, any existing barrier to the efficient procurement of facilities, goods and services will be considered.” The Commission considers that a progressive approach to the inclusion of social and human rights considerations in the procurement process should be taken, taking account of the participation of service users and also ensuring that cost considerations do not take priority over quality ones through the incorporation of human rights standards linked to quality in the specifications, selection and award criteria of the procurement process.⁹

Joint Strategic Commissioning- Professionally led locality planning and commissioning of services

It is welcome that the role of clinicians, social care professionals and the third and independent sectors in the strategic commissioning of services will be strengthened. However, it is notable that there is no recognition of the role of those who use services and their carers in the commissioning processes. The participation of individuals in decision making and where appropriate the design of services is regarded as a core procedural component of the human rights framework, helping to ensure that systems are responsive to the particular needs of disadvantaged group

⁹ For further detail see Commission’s Submission to Scottish Procurement Directorate- Joint Improvement Team Social Care Procurement Scotland Guidance, April 2010- <http://www.scottishhumanrights.com/application/resources/documents/SocialCareProcurementConsultation.doc> and Scottish Government Guidance on Social Care Procurement- <http://www.jitscotland.org.uk/actionareas/commissioning/procurement/>

rights and should be taken account of in these proposals.¹⁰

Furthermore there requires to be a recognition that for health and social care professionals to effectively engage in joint strategic commissioning practices that a corresponding culture towards an outcomes based approach for individuals must take place. As outlined elsewhere in this submission it is considered that emphasising the human rights basis of service delivery will assist in ensuring the necessary culture shift takes place.

Workforce and Leadership development

The proposals acknowledge the importance of additional “landscape changes” beyond the scope of the proposed legislation such as workforce development and leadership development. The Commission’s response to this consultation emphasises this need for cultural change in order that professionals can effectively participate in locality planning within an outcomes based framework. The Commission believes human rights should be of central consideration in ensuring decision making is outcome focused while paying regard to vulnerable groups and ensuring all services are of a requisite minimum standard for all persons.

In an environment where there may be financial constraints a human rights framework can assist balanced decision making between essential minimum services and standards and the progressive realisation of rights. The Commission would encourage key partners such as NES and SSSC to consider where human rights professional and workforce development currently sits within educational and training requirements.

Furthermore, amongst frontline workers there can be shown to be support for this approach. A follow up research survey to the Care about Rights project distributed to the care sector demonstrated that 94% of respondents thought more awareness of human rights was needed in the sector, 56% thought it should be mainstreamed within existing qualifications and 63% thought the materials would benefit other professionals, particularly healthcare professionals. The State Hospital evaluation demonstrated, amongst other things, how a human rights based approach being taken in all decisions, related to treatment and care, restrictions of freedoms, employment practice and other areas had led to a fairer environment and better relations between staff and patients.

There is therefore evidence of strong and widespread support for integrating human rights into professional and workforce development and a recognition of the cultural change this may make to the health and social care sector.

Conclusion

The proposals highlight a number of issues to be considered as the balance of care shifts from institutional and acute services to services based in the community, for example, the increased vulnerability of people being supported in their own homes and the need for effective protection, regulation and monitoring, the impact on carers and the sharing of data between services.

¹⁰ E.g. Article 25 ICCPR interpreted to cover “all aspects of public administration, and the formulation and implementation of policy”, Human Rights Committee, General Comment No. 25; UN CRPD, Article 4 on general principles; article 21 on access to information; article 26 on support for participation; article 29 on right to participate in public life.

In essence the integration proposals are intended to remove barriers in the current system that prevent services being integrated around the needs of the individual, their carers and family, giving priority to the needs of patients and service users rather than organisational needs. The Commission welcomes this intent but recognises that removal of structural barriers alone is unlikely to lead to the changes required to improve outcomes and that even within the proposals outlined with joint accountability and flexible financial mechanisms that tensions over resourcing may persist and professionals involved in commissioning and planning may lose sight of the rights and needs of the end service user or patient. As recognised in the proposal document there will be a need for development of professional skills and leadership which arguably therefore must include a robust human rights underpinning. The nationally agreed health and social care outcomes and related indicators and measures provide an opportunity to reflect the full range of human rights protection related to health and social care.

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