

Human rights in mental health care in Scotland

A REPORT ON PROGRESS TOWARDS
MEETING COMMITMENT 5 OF THE
MENTAL HEALTH STRATEGY FOR
SCOTLAND: 2012-2015

SEPTEMBER 2015

Contents

Acknowledgements	ii
A note on terminology	ii
Foreword by the Minister for Sport, Health Improvement & Mental Health	3
Executive Summary	5
Preamble	5
Aims	5
Focus and parameters	5
The approach we have taken	6
Our reflections and recommendations	6
Preamble	9
Focus and parameters of our work regarding Commitment 5	9
What do we mean by 'rights-based' and how does this apply to mental health and social care?	11
The proportionality principle	12
How we are addressing Commitment 5	14
Underpinning principles	14
What have we done so far?	14
About this report	16
Logic model – working version	17
Summaries of work contributing to the short-term outcomes	18
Understanding of levers and barriers to claiming human rights is increased among organisations	19
Service users and carers have increased knowledge of their rights	21
Strengthened capacity, capability and improved pathways for advocacy and other human rights support	24
Increased awareness of individual and systemic stigma and discrimination	26
Services & workforces have increased awareness of human rights & increased knowledge of good practice	28
Increased self-efficacy & empowerment among service users & carers	34
Shared understanding of a quality human rights service and standards	39
Opportunities to strengthen human rights focus in Scottish law and policies are increasingly identified	42
Organisations & services become increasingly effective via learning from service reviews & best experiences /practices	45
Our reflections and recommendations	46
Some context and caveats	46
How a focus on rights might be strengthened	46
Appendix A: The legislative context for human rights	53
Appendix B: Partners and stakeholders	55
Steering group	55
Organisations represented at the meetings and interviews in 2015	55
Appendix C: Glossary of acronyms	56
References	57

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A note on terminology

While we acknowledge that the term 'service user' is a contested term for people with lived experience of mental health, we have opted for its use in this report to refer to people who have used services for mental health and social care. The adoption of this term was discussed and accepted at the stakeholder consultation event in December 2014.

We use the terms human rights and rights interchangeably. Thus, at times, we use the term 'rights' as shorthand for human rights. Please see [Appendix A](#) for an explanation of the human rights framework to which we are referring.

Foreword by the Minister for Sport, Health Improvement & Mental Health

The Scottish Government has a deep commitment to the creation and promotion of a culture of fairness and equity. Scotland's National Action Plan on Human Rights identifies our vision: "Scotland is a country where everyone is able to live with human dignity".

Our Mental Health Strategy 2012-2015 reinforced that commitment, identifying as a key theme a focus on the rights of those with mental illness and the people who are involved in their care and support. The Mental Health (Care and Treatment) (Scotland) Act 2003, supported by the Adults with Incapacity (Scotland) Act 2000, established the core principles of embedding rights at the heart of practice within services. In the Mental Health Strategy the Scottish Government made the commitment to work with the Mental Welfare Commission and the Scottish Human Rights Commission to develop and increase the focus on rights as a key component of mental health care in Scotland.

This report is an important step forward in identifying the wide range of good practice and key activities across the Scottish landscape which are taking us towards fully embedding a culture of human rights. This report reaffirms the components of a rights based system using a focus on the three pillars of empowerment, ability and accountability. Empowering people to know and claim their rights; and increasing the ability and accountability of individuals, organisations and relevant professionals who are responsible for respecting, protecting and fulfilling rights.

I commend all the organisations involved for their hard work and focus on this area and would encourage their continued good work. I appreciate that not all organisations could be involved and would also like to commend the ongoing commitment and work that individuals and local organisations continue to take forward on a daily basis across Scotland.

This report acknowledges that addressing human rights in mental health care is a large agenda. It identifies some important challenges and opportunities for the future in realising people's human rights. The main purpose is to further stimulate ideas, discussion and ultimately improved outcomes for the people of Scotland.

The recent passing of the Mental Health (Scotland) Act 2015 provides a further focus for enhancing and strengthening the support around involvement and safeguarding for individuals and will assist progress in taking forward rights based work, further embedding the principles and moving us further towards a fully human rights-based mental health system. The recent announcement of increased funding of £100m for mental health services across Scotland will support this work.

A human rights-based approach is about ensuring that both the standards and the principles of human rights are integrated into policy making as well as the day to day running of organisations. As we approach the end of the current Mental Health Strategy, I look forward to continuing to be involved and engaged in this key area of work across Scotland in general, and mental health in particular, working with all

stakeholders to ensure that the added value of a human rights-based approach is embedded and how it will underpin all other principles of good practice.

Jamie Hepburn

Minister for Sport, Health Improvement and Mental Health

Executive Summary

Preamble

A key theme of the Scottish Government's Mental Health Strategy 2012-2015 is to focus on the rights of people with mental illness. Commitment 5 of the Strategy states:

We will work with the Scottish Human Rights Commission and the Mental Welfare Commission to develop and increase the focus on rights as a key component of mental health care in Scotland.

This report by the Mental Welfare Commission (MWC) and the Scottish Human Rights Commission (SHRC) for the Scottish Government seeks to understand and share insights on how mental health and social care services and agencies are working towards a common vision to meet the human rights of service users and carers. At this stage, our main focus is on agencies and services with a national remit.

Aims

We aimed to:

- identify some of the key activities that have taken place or that are planned by a sample of organisations in Scotland we consider key to progressing the human rights agenda and the changes that these organisations are expected to effect;
- identify challenges and opportunities for the future in realising people's human rights

Focus and parameters

Addressing human rights in mental health care is a large agenda. Our focus is on the human rights of people who use, or have used, statutory services for mental health (including forensic) and social care services, including children, young people and adults.

The equally important human rights of people using services for learning disabilities and for dementia lie outwith the scope of this report as they are the focus of other strategic commitments.

A human rights-based approach is a way of **empowering** people to know and claim their rights; and increasing the **ability** and **accountability** of individuals, organisations and professionals responsible for respecting, protecting and fulfilling rights.

The approach we have taken

The process so far has involved *starting*:

- to build consensus among a range of mental health and social care stakeholders on what we **collectively** are trying to achieve in our human rights work towards the outcome of a human rights-based mental health system
- to identify the **contributions** that 17 key organisations and services are making to these outcomes
- to analyse where these collective contributions leave us, in Scotland, in terms of the overall goal of building a human rights-based mental health system - what gaps remain and what might be done to fill them

It has also involved **consulting with people who use services** on their understanding of rights, on their views and experiences regarding human rights in practice, and on what they consider to be the main gaps.

Our reflections and recommendations

Some context and caveats

This work and the report that arises from this, is neither a comprehensive nor a systematic mapping exercise.

The insights that we have gathered provide a basis for our identification of some of the ways that a rights-based mental health infrastructure and ‘system’ in Scotland might be strengthened, and thereby move us towards more equitable and consistent realisation of human rights.

We offer our reflections and recommendations within the context of an ongoing process, and in anticipation of a new mental health strategy for Scotland.

Our recommendations

We have developed a series of recommendations that are informed by the conversations that we have had with organisations and services, and people who have used mental health services. We summarise these recommendations below.

1. The next mental health strategy should be explicitly built around a rights-based approach. It should utilise the human rights framework to shape its aims and mainstream human rights across its commitments. In doing so, it should be informed by the lived experience of service users and should align with the aims of Scotland’s National Action Plan for Human Rights.
2. The next mental health strategy should include measures to address stigma, discrimination and lack of reasonable accommodation, and improve awareness of the rights of people with mental health issues in mainstream health and social care services. Efforts to combat stigma and discrimination should recognise, maintain and build on existing work to view these as a matter of realising the human rights of those affected by stigma and discrimination.

3. Integrated human rights and equality impact assessments should be routinely deployed in the development of mental health policies, practices, procedures and priorities: doing so offers a mechanism for identifying, addressing and embedding equality and human rights considerations.
4. We recommend a review and subsequent consolidation of existing training initiatives across the mental health workforce against the human rights framework, and with reference to the Convention on the Rights of Persons with Disabilities. This should be used to provide national leadership and direction to all sectors of the health and social care workforce as to how to further embed human rights in workforce development.
5. The Code of Practice accompanying the Mental Health (Care and Treatment) (Scotland) Act 2003 should be revised to involve explicit connections to human rights principles and to the human rights framework. Doing so will help to embed rights based practice.
6. The Scottish Government should issue a Chief Executive letter to Health Boards setting out clearly the expectations on Boards to promote the wider use of advance statements, and should consider what national guidance and support should be made available to support this. This should reflect the new duties in section 26 of the Mental Health (Scotland) Act 2015, drawing on the experience of existing projects seeking to build such support and the work of the MWC-led group on advance statements.
7. The Scottish Government should coordinate interagency discussion and action at a national level to explore issues of capacity and supported decision-making. Efforts should be focused on strengthening existing forms of supported decision-making and identifying how further models can be developed which reflect the Scottish legal and service context, and respond to the implications of the UN Convention on the Rights of Persons with Disabilities.
8. There should be further exploration of ways for service users to be provided with consistent, reliable and accessible information on rights, prior to and during crisis points, with opportunities for them to be reiterated at key points during care and treatment. The manner in which this should be provided should be informed by the lived experience of service users.
9. We recommend the development of an online portal bringing together and making accessible rights-based materials, evidence and best practice. The content of this portal should be quality-controlled and curated to ensure that it remains focussed on content which is explicitly rights-based.

Further reflections

In addition to the recommendations detailed above, we consider that an improved focus on rights would be well-served by:

- clearer and more precise specification of which rights various services and organisations are addressing in order to aid transparency and to enable identification of any gaps
- proportionate monitoring and evaluation by organisations and services
- understanding and evidencing the extent to which integrated services are effectively promoting service user empowerment and self-efficacy
- consideration of how we reach the most vulnerable sectors and groups in society, not just by making information available to them, but crucially in order that they are better empowered to have their human rights met
- establishing a shared language for human rights and ensuring that this is comprehensible and appropriate to lay people
- discussion and debate around the application of the proportionality principle in balancing risk and quality of life considerations
- consideration of how to address the pressures faced by Mental Health Officer services in meeting the expectations of the Mental Health (Care and Treatment) (Scotland) Act 2003 and the Adults with Incapacity (Scotland) Act 2000
- improved access to, and quality of, advocacy
- services considering how recovery focused they are, and following through on opportunities for improvement
- specific attention being given to progress and challenges in meeting the rights of people being treated under forensic services, including those under community treatment orders
- exploration of service users' understanding, views and experiences of accountability procedures e.g. whether people know where to seek redress and have support to do so (whether advocacy or legal support); the accessibility of legal and complaints mechanisms; and meaningful redress

We hope that this report will serve to further stimulate ideas, discussion and improved outcomes.

Preamble

A key theme of the Scottish Government's Mental Health Strategy 2012-2015 is to focus on the rights of people with mental illness. Commitment 5 of the Strategy states:

We will work with the Scottish Human Rights Commission and the Mental Welfare Commission to develop and increase the focus on rights as a key component of mental health care in Scotland.

The Scottish Government¹ has been working with the Mental Welfare Commission (MWC) and the Scottish Human Rights Commission (SHRC) to consider how it can address this commitment. This report by the MWC and the SHRC for the Scottish Government seeks to understand and share insights on how mental health and social care services and agencies are working towards a common vision to meet the human rights of service users and carers. At this stage, our main focus is on agencies and services with a national remit.

While organisations may implicitly incorporate human rights, Commitment 5 seeks to increase the focus on rights as a key component of mental health care. We are therefore looking at how the system can take a more **conscious** rights-based approach to ensure, and not simply assume, that rights are delivered.

By illuminating where progress is being made, and where progress is likely to be slower, we will be better placed to understand whether, and how, the human rights of service users and carers will be upheld, addressed and satisfied, and importantly – where additional focus and energies are needed.

This report is intended to help us all move forward in this *process*. The report is not an end-point. It is a step forward in conceptualising where we collectively want to go, whether we are likely to get there by doing what we are currently doing, and identifying what else might need to happen.

As the Scottish Government's Mental Health Strategy 2012-2015 comes to an end, we intend that this work will inform the next set of priorities and commitments to action. We see real potential for the next mental health strategy to address the gaps and opportunities identified, to move us towards our common vision.

Focus and parameters of our work regarding Commitment 5

Addressing human rights in mental health care is a large agenda. While the focus of the work described herein includes the human rights of children, young people and adults, the content of this report and the process that produced that content are circumscribed by a focus on people who use, or have used, statutory services for mental health (including forensic) and social care services. Such individuals may also receive input and support from third sector organisations.

¹ To date, the Scottish Government perspective has been provided by its Mental Health Adviser

The equally important human rights of people using services for learning disabilities and for dementia are issues that lie outwith the scope of this report. This is because they are the focus of other strategic commitments².

We have considered the components of a rights-based mental health system primarily from the angle of policy and practice. Accordingly, we have focused on the activities of agencies and services who contribute towards that system. As we intend for this work to inform the next mental health strategy, the intended audiences for this report are policymakers and stakeholders operating within the system.

We firmly believe that it is essential to consider the views of people with lived experience of the mental health system. Their views and experiences are crucial to understanding whether their human rights are being realised in practice, and indeed the identification of gaps and weaknesses within the system. The MWC commissioned research to uncover such perspectives, and we describe this later.

We are also aware of work that is underway, from a primarily lived experience perspective, to establish a rights framework for mental health and to recommend how provision might change and develop in order to better support people in accessing their rights. We view this work as essential in bringing a lived experience perspective which will, in time, complement this report.

² For learning disability, see The Keys to Life and associated Implementation Framework; for dementia, see Scotland's National Dementia Strategy 2013-16

What do we mean by ‘rights-based’ and how does this apply to mental health and social care?

In the current landscape of the integration of health and social care services, a focus on human rights offers a common language and framework to help public bodies and their partners stay focused on their key purpose – to improve people’s lives.

Under Commitment 5, we are concerned with the basic rights and freedoms to which we are all entitled, but specifically as they apply within the context of the mental health and social care system. A detailed explanation of the legislative framework for this is provided in [Appendix A](#).

In this section, we define the term ‘rights-based’. Such clarification can be useful to identify false positives (where an organisation thinks of itself as rights-based but does not take active steps in this regard) or false negatives (where an organisation does not identify as rights-based but is, in fact, engaging in strong rights-based practice).

The components of a rights-based mental health system focus on the three pillars of empowerment, ability and accountability. Thus, a human rights-based approach is a way of: **empowering** people to know and claim their rights; and increasing the **ability** and **accountability** of individuals, organisations and the relevant professionals who are responsible for respecting, protecting and fulfilling rights.

This means giving people greater opportunities to participate in shaping the decisions that impact on their human rights. It also means increasing the ability of those with responsibility for fulfilling rights to recognise and know how to respect those rights, and making sure they can be held to account.

A human rights-based approach is about ensuring that both the standards and the principles of human rights are integrated into policy making as well as the day to day running of organisations.

The application of human rights in policy making and day-to-day practice is formulated as a framework of **PANEL principles** – an acronym for Participation, Accountability, Non-discrimination and equality, Empowerment and Legality. A rights-based organisation would incorporate each of the PANEL principles in its capacity as an employer (in its treatment of staff) and as a service provider (in engaging with its target groups).

Table 1: PANEL principles

P articipation	Everyone has the right to participate in decisions which affect them. Participation must be active, free, and meaningful and give attention to issues of accessibility, including access to information in a form and a language which can be understood.
A ccountability	Accountability requires effective monitoring of human rights standards. For accountability to be effective there must be appropriate laws, policies, administrative procedures and mechanisms of redress in order to secure human rights.
N on-discrimination and equality	A human rights-based approach means that all forms of discrimination must be prohibited, prevented and eliminated. It also requires the prioritisation of those in the most vulnerable situations who face the biggest barriers to realising their rights.
E mpowerment	People should understand their rights, and be fully supported to participate in the development of policy and practices which affect their lives. People should be able to claim their rights where necessary.
L egality	The full range of legally protected human rights must be respected, protected and fulfilled. A human rights-based approach requires the recognition of rights as legally enforceable entitlements, and is linked in to national and international human rights law.

The PANEL principles accord closely with the principles of the Mental Health (Care and Treatment) (Scotland) Act 2003. The elements of Participation and Empowerment will be familiar to many; however, a human rights-based approach also requires the recognition of rights as legally enforceable entitlements, linked to national and international human rights law. We consider that a “rights-based” organisation or initiative would include explicit recognition of the Legality of rights which underpin what the organisation is doing. The Legality element is key and forms the objective foundation of a rights-based approach. It reflects the constant nature of the legal duties placed on public authorities to respect, protect and fulfil human rights, which should guide policy and practice. Without a working understanding of human rights and an explicitly human rights-based culture, a service may be engaging in aspects of good practice, or person-centred care but it may not necessarily be “rights-based”, in having a full understanding of what that means in practice for every individual or situation, with the potential for breaches of human rights to occur.

The proportionality principle

One of the aspects afforded by the legal framework of human rights is the concept of proportionality, which lies at the heart of many rights. It means that an intervention which affects a certain qualified right, such as the right to privacy and physical and psychological integrity, must be thought through to ensure that it is the minimum

required to achieve the desired aim without unduly restricting someone's rights³. A full understanding of concepts such as this means that a human rights-based approach in mental health care can assist in balancing risk and quality of life considerations and can provide a common framework of rights and responsibilities for everybody. This idea is embedded in the Mental Health (Care and Treatment) (Scotland) Act 2003 and the Adults with Incapacity (Scotland) Act 2000.

Understanding the balance of these rights and duties provides a framework for making difficult decisions, keeping a person-centred approach at heart. A "rights-based" organisation would incorporate this fundamental aspect of human rights law into its policies and practices, laying strong foundations for delivering on these other legal duties. To make sure this happens it is, however, important to maintain a clear link to human rights in practice – to ensure and not assume compliance when delivering on other duties. This is just one example of the added value of human rights-based approach and how it must underpin all other principles of good practice.

Why take a "human rights-based approach"?

Many organisations we spoke to explained that rights were core to everything they do or that they were implicit, for example in training resources. Rights were often described as part of the ethos, spoken of in terms of person-centred care or recovery or as a question of professional values. There are indeed strong parallels with all of these. However a rights-based approach adds a further, complementary, layer to these.

Explicit recognition of human rights has been found to help improve institutional culture, reinvigorating a public service ethos among staff, and 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, a human rights focus helps reinforce the purpose of public service – to improve people's lives.

A focus on human rights can usefully shift organisational culture from being based on subjective and potentially disempowering notions of what "recipients" of services are believed to want and need: it offers a more objective basis for delivery, based on a legal duty to fulfil human rights and can empower individuals by placing emphasis on their wishes and preferences.

A rights-based approach is inherently person-centred as it puts the individual, their views and their rights, for example to choice, control and autonomy, at the centre of decision making. Furthermore human rights provide a shared framework for communication between professionals, individuals using services and family members, helping to resolve any tensions in the way in which care and treatment are delivered.

³ To understand better how this works in practice, see the FAIR flowchart, available here <http://www.scottishhumanrights.com/careaboutrights/flowchart>

How we are addressing Commitment 5

Underpinning principles

The approach being taken by the MWC, SHRC and the Scottish Government in relation to Commitment 5 is a consultative and collaborative one, and builds on the earlier work done to gather the experiences of people using services. The material provided in this report is based on discussions with senior stakeholders representing statutory and third sector agencies and services, mostly with a national focus, in Scotland, and the views of service users and carers. As indicated earlier, our approach is an iterative one, and what we have so far is a snapshot: while we draw on the discussions with a range of people, the picture that has been captured and reported here will inevitably be a partial one.

The approach that is being taken is outcome-focused. Thus, the focus is not simply on what is being done by organisations and services, but on seeking to understand their likely or known effectiveness in bringing about intended **change**. We are aware that all of the organisations consulted during this process are working towards their own outcomes and strategic priorities. We have sought in this report to identify where these overlap with, or complement, each other and where gaps exist in the overall picture of improving human rights in the mental health and social care system.

What have we done so far?

The process so far has involved starting:

- to build consensus among a range of mental health and social care stakeholders on what we are **collectively** trying to achieve in our human rights work towards the outcome of a human rights-based mental health system
- to identify the **contributions** that some key organisations and services are making to these outcomes
- to analyse where these collective contributions leave us, in Scotland, in terms of the overall goal of building a human rights-based mental health system - what gaps remain and what might be done to fill them.

It has also involved **consulting with people who use services** on their understanding of rights, on their views and experiences regarding human rights in practice, and on what they consider to be the main gaps.

The process has been developed and overseen by a steering group comprising representation from MWC, SHRC and the Scottish Government ([see Appendix B](#)) and each of the steps taken is briefly described below.

Building consensus on outcomes

Stakeholders were invited to a workshop to discuss the high-level strategic outcomes for mental health and social care in Scotland in increasing the focus on human rights.

This involved obtaining views and feedback on a logic model⁴, which were integrated into a refined draft which is provided on page 17.

This logic model shows our current thinking on the specific changes (outcomes) that are expected to happen as a consequence of the activities of organisations and services within the mental health and social care 'system'.

It is acknowledged, however, that this model will require further refinement.

Identifying organisations' and services' contributions to strategic outcomes

In order to find out what activities may currently be happening which contribute towards the identified strategic outcomes, meetings were held with senior stakeholders from 17 organisations and services. These involved focused discussions around the logic model, and identifying which short-term outcome(s) each organisation or service felt it was contributing to through its own work, and how. Each of these meetings was facilitated by a representative from the MWC, SHRC or the Scottish Government using a pre-developed template. This template was used to capture information from each organisation on all relevant short-term outcomes in the logic model regarding: the specific changes that were considered to be realistically achievable over the next two years as a consequence of the organisation's own activities; the challenges and gaps that this organisation faced in effecting changes; and views on 'system wide' gaps and potential solutions that may impinge on success. [Appendix B](#) lists the organisations involved in the meetings described above.

Consulting with service users

In 2013, the MWC commissioned research to explore: the extent to which people with mental health problems know what their rights are when they access services; views on how well services are respecting people's rights; and people's priorities for change. The focus of this study was specifically on people who have used NHS and local authority mental health services, and their views on these services⁵.

In June 2015, a consultation event was run as one of the parallel workshops at the Rights for Life national conference (organised and hosted by the Scottish Recovery Network (SRN), See Me and Voices Of eXperience (VOX). Thirty people participated in this workshop, most of whom were using, or had used, mental health services. Their views and experiences were explored in relation to human rights matters concerning: empowerment; service organisation and delivery; and accountability – their understanding about what to do if they feel that their rights are not being respected and views on the effectiveness of the existing laws, complaints mechanisms and rights bodies.

⁴ A logic model shows intended outcomes (changes) in the short-, intermediate- and long-term, and the activities that are expected to produce these.

⁵ Griesbach D and Gordon J (2013) Individuals' rights in mental health care
http://www.mwccot.org.uk/media/129344/rightsinmentalhealth-report-final_apr_2013.pdf

About this report

This report is primarily intended for strategic planners and policy makers. In the pages that follow, we distil information from the meetings with organisations *on their reported contributions* to the short term outcomes in the logic model. ***It is important to acknowledge that the activities that are reported here will not be a comprehensive account of all that the organisations involved are doing in relation to the various outcomes. Moreover, the report does not include everything that is happening across Scotland that might, or does, contribute towards the outcomes listed. Thus, we are conscious that there will be organisations and services outwith those to whom we spoke who will be contributing to the high level outcomes explicated in the logic model.***

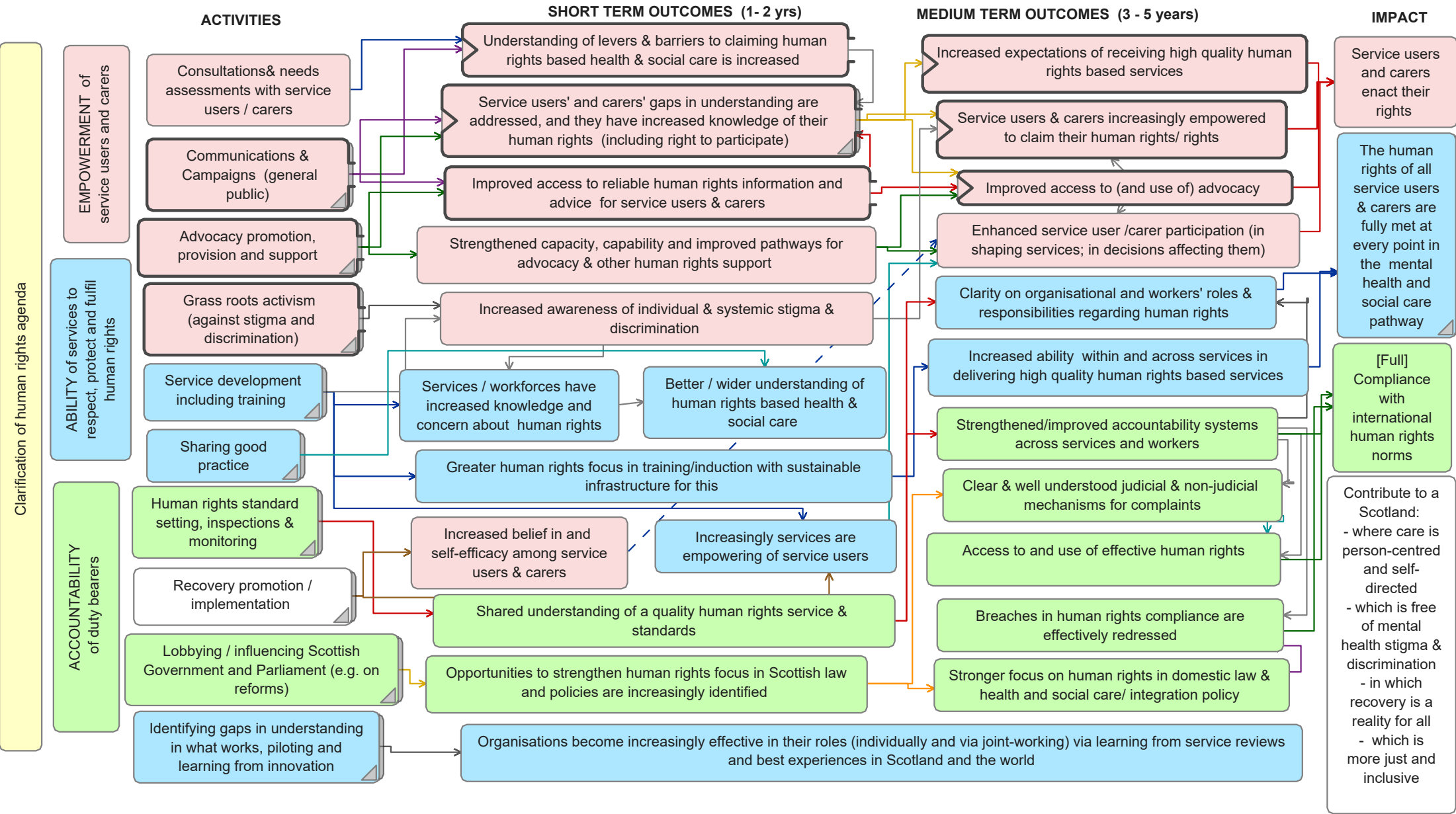
In this report, we also consider and integrate the views of service users obtained at the Rights for Life workshop and the MWC commissioned research.

We present the short-term outcomes from the logic model in turn, and summarise the changes that would be expected to arise as a consequence of activities currently underway, and some of the key factors that organisations have highlighted – organisational or elsewhere in the system – for their success. In addition, we pepper the report with short good practice examples of some of the activities being carried out by organisations, in order to breathe life and colour into the report, to provide additional detail, and to share a few of the interesting and important developments and initiatives that are happening.

We conclude the report with our reflections on what this information seems to tell us in the round; where there are cross-cutting challenges; and some ideas and recommendations about how our collective impact might be strengthened.

In doing so, we hope that this report advances our ongoing learning, usefully fuels national and organisational debate, and contributes to system-wide improvement.

Logic model – working version



Summaries of work contributing to the short-term outcomes

In pages 18 to 45 of this report, we consider the short-term outcomes in the logic model, and summarise what stakeholders indicated that their respective organisations are doing in relation to these.

We do not claim to provide an exhaustive account of everything that they were doing, however. We have identified key activities, most of which are ongoing rather than 'one-off'.

Understanding of levers and barriers to claiming human rights is increased among organisations

What is being done

A number of focused events have been organised and hosted that are intended to deepen understanding, within organisations and workforces, of the range of issues that impede service users and carers claiming their human rights.

These events have taken the form of conferences, community engagement activities (e.g. 'community conversations'), consultations and commissioned research – and the production of reports on the insights gathered from these various approaches.

See Me and its ongoing learning from people with lived experience of mental health

See Me is facilitating a series of rights-based conversations in communities. These 'community conversations' are intended to empower communities in contributing to change in their local communities, and to serve as action research for See Me by helping it learn from grassroots ideas and activities. See Me will support a selection of the ideas that emerge from these conversations through its Community Innovation Fund. The funding criteria for this fund are explicitly rights-based. Additionally, ideas may be actioned by communities independently. A toolkit will be produced to help communities carry out conversations themselves.

The community conversations and funded projects contribute not only to the understanding of See Me (and partner organisations) but also to increased awareness more generally.

The Health and Social Care Alliance Scotland (the ALLIANCE) co-convenes the SNAP Health and Social Care Action Group. A website has been developed⁶ and film and written case studies have been produced to illustrate the application of human rights approaches in practice.

In addition, there was mention of ancillary activities that *contributed* to increased understanding of levers and barriers, although not necessarily as their core purpose. Examples included service providers' use of tools and resources such as the Scottish Recovery Indicator 2 (SRI2), the National Self Directed Support (SDS) website, the Scottish Patient Safety Programme and advocacy services. Finally, there was mention of ongoing involvement of service users and carers in shaping decisions about organisations' focus and practices.

Participants at the Rights for Life workshop valued the involvement of service users and carers in service development, and they felt that the application of SDS, in its purest form, was consistent with a rights agenda.

⁶ <http://www.healthandsocialcare-snap.com/>

Limitations

One-off events and hard copy publications were acknowledged as having a limited life and requiring regular updating. Later we provide, as an example, how this has been addressed by the Rights for Life conference, and subsequent developments.

While the various activities and outputs were intended to increase understanding, evidence was generally lacking on whether or not this had actually happened.

The reach of events was acknowledged to be limited. Furthermore, there was acknowledgement that those attending events may already have an interest in the topic under consideration, and therefore a high level of understanding.

Systemic issues

While awareness and discourse on human rights were seen to have increased, it was felt that there is an outstanding need for more explicit use of the language of human rights. It was felt that this would provide a more robust legal and value base, and more clarity about the contributions that organisations are making to the rights agenda.

At times, there was a perceived tension between balancing the human rights of individual service users and at the same time, addressing the human rights of other patients and indeed staff. These tensions seemed to arise most keenly in relation to rights regarding safety, privacy and freedom (although, as discussed on page 12 above, a full understanding of the human rights framework and, in particular, the proportionality principle, can help to address these tensions). The pervasiveness of a risk-averse culture was regarded as an important contextual issue in this regard. These tensions were highlighted by service users too.

Service users participating in the Rights for Life event felt that stigmatised attitudes in services impacted on their care, including their rights.

There are reports and resources that provide insights on service users' and carers' views and experiences but these are not always widely known about or used. These are therefore untapped opportunities for organisations to better understand levers and barriers to claiming rights.

The reasons for people not creating advance statements were generally not well understood.

Service users and carers have increased knowledge of their rights

This chapter focuses on what is being done to improve understanding of human rights among people who use services and carers, and how effective these activities are. There are two dimensions to this: deepening understanding among individuals by filling their gaps in understanding, and improving the knowledge of the population of users and carers. This distinction is an important one: to achieve population level impact, it will be necessary to ensure understanding among the full range of individuals and groups affected. This will include those less likely to know their rights and most at risk of inequalities e.g. people from different educational or socio-economic backgrounds, black and minority ethnic (BME) groups etc.

In the logic model, there is also a more modest outcome that feeds into this: that users and carers have better access to information and advice. As the purpose of enhanced access is improved understanding (i.e. that more people understand their rights, and/or that their understanding is deepened), we integrate the information that was collected in relation to improved access with the information collected in relation to improved knowledge.

What is being done

A statement of rights and an agenda for change are being developed by See Me, SRN and VOX, building on conversations and insights from the Rights for Life conference (see box below) and through further consultation.

Rights for Life as part of an ongoing process

Rights for Life was a national event co-organised by SRN, See Me and Voices of eXperience (VOX). Designed to be solutions-focused, engaging and positive, this was a free two-day event that ran in June 2015. It involved over 60 speakers and hundreds of delegates and focused on rights, mental health recovery, stigma and non-discrimination, dealing with high level issues (e.g. self-management and employability) through to specific issues such as advance statements.

This innovative conference was streamed live and those accessing it online were able to contribute to live discussions through teleconferences and webinars. Learning from this event is captured and available via a dedicated website at <http://rightsforlife.org>.

Rights for Life is part of an ongoing *process* to increase awareness about mental health rights, tackle discrimination and contribute to recovery. It is intended that the statement of rights will provide a catalyst / mobilising force for people advocating for change (adding impetus to See Me's social movement programme).

The Mental Welfare Commission (MWC) produces good practice guides. These are explicitly rights-based and are available in print form and also online. The currently available guides were initially developed mainly for practitioners, and following a

commissioned evaluation of these materials⁷, a more user-friendly series is being developed over 2015/2016 specifically to meet the needs of service users and carers.

The MWC also provides an advice line offering advice on rights to both professionals and people using services. This takes approximately 2000 calls per year from service users and carers. The MWC intends to review this advice line in the next 12 months, and will include in that review consideration of how effective it is in helping service users and carers understand and realise their rights.

Targeted awareness-raising to organisations' respective client groups / service users were also identified. Examples include the SAMH induction for all new service users and staff. This includes a factsheet detailing rights when at work, living in the community, when receiving care and treatment, when claiming benefits and when they buy or rent property.

NHS Lanarkshire provides funding to, and consults with, a mental health service users' and carers' organisation, and uses this as a conduit to increase understanding of rights.

An awareness campaign is being developed under the auspices of the SNAP Better Culture Action Group. This is intended to help the general public understand why rights matter and empower them to claim these. Although this will not be specific to mental health and social care, it will cover issues relevant to service users and carers in terms of their overall human rights.

SAMH's signposting guide - Know Where to Go – is available via GP surgeries and includes a short guide to rights.

Limitations

Services acknowledged that limited reach will be an issue. Furthermore, while some service users at the Rights for Life workshop talked of Mental Health Officers (MHOs), nursing staff and libraries as helpful sources of information, generally (perceived) lack of access to information was an important issue for them. This may reflect lack of awareness of the sources of information that are available.

Research previously commissioned by MWC reinforces this lack of awareness⁸. In that research, very few people knew what their rights were. This was the case even among those who had experience of being hospitalised, including through compulsory treatment orders. The authors of this report comment that the finding is particularly notable in view of the fact that their recruitment had been via mental health support groups i.e. the research participants were people who one would perhaps expect to be better informed than service users more generally.

⁷ Griesbach D and Platts A (2014) Practitioner views on the Mental Welfare Commission's good practice guides http://www.mwscot.org.uk/media/191992/practitioner_view_of_guides_-_report_-_final.pdf

⁸ Griesbach D and Gordon J (2013) Individuals' rights in mental health care http://www.mwscot.org.uk/media/129344/rightsinmentalhealth-report-final_apr_2013.pdf

Systemic issues

In the MWC research, service users indicated a distinction between knowing one's rights versus understanding what enactment of those rights would look like *in practice*. Other issues raised were: understanding the circumstances in which carers had rights (and what these rights were); the timing and frequency with which people are informed of their rights (and the view that being only told of rights at a time of high levels of agitation and distress is insufficient); and that the rights language needs to be intelligible and jargon-free.

There is a need to make people aware of their rights not only at the point at which they are in crisis but throughout their care and support pathway. This includes the information provided at initial contact point with services, such as with primary care and general practitioners. At these junctures, people need to be made aware of the rights that apply to them at that point in time as well as being signposted to sources of further information and support.

The information that is available through providers such as the Citizens Advice Bureau and other third sector organisations, including advocacy groups, is an unknown.

There were concerns that insufficient availability of MHOs may result in service users 'missing out' on conversations about their rights.

Strengthened capacity, capability and improved pathways for advocacy and other human rights support

What is being done

Advocacy

The Scottish Independent Advocacy Alliance (SIAA) successfully lobbied, during the passage of the Mental Health (Scotland) Bill, for more robust scrutiny of advocacy service provision. The Bill received Royal Assent on 4 August 2015 and should be fully implemented by September 2016. When the relevant provisions are brought into effect, health boards and local authorities will be required to inform the MWC on how they have ensured access to independent advocacy for people with mental health problems (and learning disability). The MWC intends to monitor that activity and regularly report on it. It is envisaged that this should lead to gaps in provision being identified and filled.

The ALLIANCE and SIAA are working with the Scottish Government to pilot a more strategic approach to independent advocacy during the reassessment for people undergoing the transition from Disability Living Allowance (DLA) to Personal Independence Payment (PIP) as well as assessments for Employment Support Allowance. This includes a focus on people with mental health problems. Although a pilot, this is considered to offer the potential for expansion.

A training package for advocacy workers is being developed by the SHRC and the Scottish Independent Advocacy Alliance (SIAA) in order that they are better informed and equipped to promote human rights with, and for, their clients.

SIAA has been running a Quality Assurance Pilot Project which involved six advocacy organisations undergoing an independent evaluation using the **SIAA Evaluation Framework**. The aim of the evaluation is to measure the quality of the work of the organisation. The evaluations were carried out by teams of individuals including advocacy commissioners, people who have used advocacy and people with experience in the voluntary sector and evaluation. The Scottish Health Council has evaluated the project and their report will be published shortly.

Advance statements

As part of its wider work on supported decision-making, SRN is supporting the Mental Health Network (Greater Glasgow) in training people to become peer volunteers. These volunteers will support people in producing their advance statements and accompanying personal statements.

The Mental Health Network (MHN) project, Greater Glasgow

The project trains people with lived experience to become peer volunteers who will support others to write an advance statement accompanied by a personal statement, and do so in terms that will communicate effectively with services, mental health teams etc. The peer volunteers also work with health practitioners, e.g. mental health nurses, CPNs and psychiatrists to help increase their awareness and understanding of

advance statements and personal statements. The MHN Volunteers also carry out awareness-raising sessions and ‘surgeries’ about advance statements. There is a dedicated website to promote this project (see: <http://www.advancestatementscotland.org/>)

The Mental Health Network (Greater Glasgow) is also developing a publicly available training resource for peer volunteers to inform service users and providers about advance statements.

A specific focus on advance statements is being taken by the MWC: in consultation with service user groups across Scotland, it will produce guidance and advice over 2015/2016.

Limitations

While advance statements offer an avenue for supported decision-making, there is a need to consider these and supported decision-making in relation to care and treatment more widely (not just in crisis care).

Systemic issues

The new Act contains provisions regarding advance statements, including establishing a register to be held by the MWC, and a requirement for Health Boards to place advance statements held by them with a person’s medical records. The Act also requires that Health Boards should publicise and notify the MWC about the support they offer for making advance statements. If these responsibilities are taken seriously, they should make it more likely that service users will feel it is worthwhile to make an advance statement, encouraging greater respect for the wishes of service users in health care.

It is widely acknowledged that advocacy provision is insufficient and that it is often limited to people under compulsory treatment orders. There were views that lack of advocacy is particularly marked for people in hard to reach groups, such as BME groups, and older people.

Article 12 (3) of the UN Convention on the Rights of Persons with Disabilities requires the state to ‘take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity’. It is not clear that enough is yet being done to achieve this for people with mental health issues.

Increased awareness of individual and systemic stigma and discrimination

What is being done

See Me is taking a multi-pronged approach to tackle stigma and discrimination. It has programmes of work focusing on children and young people, health and social care, the workplace, and communities. A cross cutting theme is the development of a social movement.

See Me – Scotland’s national programme to tackle stigma and discrimination

See Me’s vision is to end mental health stigma and discrimination, enabling people who experience mental health problems to live fulfilled lives. It is committed to ensuring that the human rights of people with mental health problems are respected and upheld.

See Me carries out a range of reactive and proactive activities, including (but not limited to):

- Generating positive media – media volunteers with lived experience promote their personal stories in the media, such as their experience of a particular mental health condition or in a particular setting (e.g. the workplace), and reacting to media stories on mental health.
- Funding community innovations – positive stories from projects receiving funding are used to challenge stigma and discrimination in local settings.
- Developing work with children and young people to support them to become more able to seek help, challenge stigma and discrimination, and understand their rights and some of the structural issues affecting their mental health.
- People Like You – a national campaign to mobilise individuals to join a national movement against stigma and discrimination.
- See Me in Work – Supporting employers to create safer places for employees with mental health conditions and realise their duties under the Equalities Act.

See Me also talks directly to institutions involved in stigmatising situations to explore the issues arising, start a conversation with them and seek a more positive outcome, such as a change in practice.

See Me aims to create a social movement to challenge stigma and discrimination. Whether this movement achieves a critical mass will be dependent on See Me’s continuation and therefore funding in the longer term.

On its website⁹, it reports having nearly 7,000 followers on Facebook and over 6,000 on Twitter; in 2014 it awarded 24 projects around Scotland a total of £185,000 for action on mental health stigma and discrimination; and, eight Community Champions have now completed their training to become leaders in their local communities, with a further 24 being trained.

The Royal College of Psychiatrists promotes equity of services for mental health via its ‘parity of esteem’ agenda. This aims to elevate mental health care to the status afforded to physical health.

⁹ Figures as reported on See Me website (<https://www.seemescotland.org/>) on 3rd August 2015

The ALLIANCE and NHS Education Scotland (NES) have developed a training pack - Emotion Matters - for health and social care professionals. This online resource¹⁰ provides seven modules to encourage professionals to consider how people feel when they are spoken to by professionals.

VOX works in partnership with mental health and related services to ensure that service users get every opportunity to contribute positively to changes in the services that serve them and wider society. Stigma reduction is one of VOX's priorities: it contributes to action to combat stigma and discrimination through direct work with service users and via collaborative working with others including See Me and SRN.

Limitations

While change is believed to be happening, societal change will not happen overnight.

See Me has made significant efforts to ground the fight against stigma and discrimination in the human rights of those experiencing them, however, this connection is not always made explicitly.

Systemic issues

There was a view that there is a general lack of awareness and understanding of mental health among the general population and that there is not yet 'parity of esteem' between mental and physical health i.e. that more value is placed on physical health issues and associated care than is the case with mental health.

In the context of mental health care, there was concern about discriminatory attitudes and practices affecting people with mental health needs in mainstream health and care services. Examples included the service responses sometimes experienced by people using emergency services for mental health crises or self-harm, and indeed other gatekeepers and practitioners: the See Me Now conference highlighted strong feelings regarding how people felt they were spoken to by GPs, NHS 24, accident and emergency services as well as within mental health services.

Sometimes such discrimination was considered to be inadvertent, for example in the phenomenon of 'diagnostic overshadowing', where health professionals assume a person's physical health problems are attributable to their mental illness. Other times, discrimination was seen to occur through a failure to make reasonable accommodation¹¹ for the particular needs of a person with mental health needs. The MWC has particular concerns about the understanding of human rights in relation to issues of consent and impaired decision making ability.

¹⁰ <http://www.knowledge.scot.nhs.uk/home/learning-and-cpd/learning-spaces/emotion-matters.aspx>

¹¹ "Reasonable accommodation" means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.' [United Nations Convention on the Rights of People with Disabilities; Article 2]

Services & workforces have increased awareness of human rights & increased knowledge of good practice

In this section, three outcomes in the logic model are considered together. These are:

- services and workforces have increased knowledge and concern about human rights (i.e. what they know about the principles of human rights and their attitudes to these);
- better understanding of levers and barriers to delivery (i.e. better understanding about how to meet human rights)
- greater human rights focus in training/induction (a mechanism for achieving the former two outcomes)

While these three outcomes were separated in the initial model to communicate and consult on whether these were in fact the changes that stakeholders envisaged, they are combined here as there is significant overlap between them.

What is being done

Showing and sharing good practice

SHRC, in partnership with others in the delivery of SNAP, has developed a series of five film case studies, which are complemented by a written guide, showcasing examples of human rights-based approaches to health and social care taken by third sector organisations.

The MWC produces a range of good practice guidance resources for professionals, with these available in print and online. These have been evaluated very positively. Additional good practice guides are being developed.

MWC good practice guides for promoting human rights under the Mental Health Act

The MWC Good Practice guides¹² are intended to support the Commission's duty to promote best practice in relation to the Mental Health (Care and Treatment) (Scotland) Act 2003. The findings from an independent evaluation¹³ of these guides indicate that they have a strong human rights focus and are well used and valued. More specifically, professionals found them relevant and useful; concise, easy-to-read, and jargon-free. The inclusion of case studies was valued for helping practitioners to apply the principles set out in the guides to the real life situations they faced.

Respondents often commented favourably on the wider work of the Commission and on the expertise and helpfulness of staff. Although respondents cited a wide range of professional bodies and published materials as other possible sources of advice, there was a strongly expressed view that the Commission was the **key** source in this area.

¹² <http://www.mwscot.org.uk/publications/good-practice-guides/>

¹³ Griesbach D and Platts A (2014)

The MWC is also developing a “patients’ rights care pathway”. This will involve identification of key points in the care pathway when practitioners should address human rights. This is in response to its commissioned research on individuals’ understanding of their rights (see pages 15 and 22). The pathway is being developed in partnership with service user groups; elements of the pathway will be tested with local services, possibly using the NHS Patient Safety Programme, and if successful, rolled out.

The Care Inspectorate (CI) hosts a knowledge ‘hub’ that includes a library of good practice guidance, information on new policies and legislation, examples of innovative practice, and resources intended to support service improvement. This hub provides information on human rights and human rights-based practice, and has a portal on human rights policy¹⁴. The CI also produces and distributes newsletters that are not specific to human rights.

Training and the provision of other learning and reflective practice opportunities

NHS Education for Scotland (NES) has produced Ten Essential Shared Capabilities (commonly referred to as 10 ESCs¹⁵). This is a resource that is intended for use by all health care staff to support their learning in approaches that are person-centred, and are rights and value-based. Training was previously cascaded to mental health nurses using a training-for-trainers model, with this delivered by Penumbra and Health in Mind. The resource is available online.

NES Training Resource - The 10 Essential Shared Capabilities for Mental Health Practice (10 ESCs)

This is a comprehensive scenario-based educational resource originally published in 2007 and updated in 2011. The learning is intended to be relevant to people in all roles and settings who are involved in mental health work.

The 10 ESCs training and learning has been widely disseminated in Scotland, particularly among mental health nurses as a result of *Rights, Relationships and Recovery: the report of the national review of mental health nursing in Scotland (2006)*.

The 2011 version builds on the successes of the original, informed by findings from an independent evaluation¹⁶, and was updated to reflect the evolving policy and legislative context. The main emphasis of the learning resource continues to focus on supporting cultural change in services by

¹⁴ <http://hub.careinspectorate.com/knowledge/policy-and-legislation/policy-portals/human-rights/>

¹⁵ The 10 ESCs are: Working in partnership; Respecting diversity; Practising ethically; Challenging inequality; Promoting recovery, well-being and self-management; Identifying people's needs and strengths; Providing person-centred care; Making a difference; Promoting safety and risk enablement; and, Personal development and learning.

¹⁶ http://www.scottishrecovery.net/images/stories/downloads/nesc_eval_of_10escs_and_rr_full_report.pdf

promoting rights-based and recovery focused practice. Explicit reference to human rights is a central theme of all modules.

The resource can be accessed at:

http://www.nes.scot.nhs.uk/media/351385/10_essential_shared_capabilities_2011.pdf

Education to support Scotland's human rights-based mental health legislation

Two learning resources covering areas requested by NHS Boards have been developed by NES. These are available in print and online.

Mental Health Care and Treatment Act

This resource was redeveloped from previous education to support implementation of the 2003 Act and was published in 2011. It was primarily designed for mental health nurses working with people with mental health problems in recognition of the fact that they have specific statutory responsibilities as well as practice responsibilities under the Act. However, as the Principles of the Act apply to all staff, it is equally relevant to the wider workforce working with people who have mental health problems as well as patients and carers.

http://www.nes.scot.nhs.uk/media/846015/interactive_mh_act_resource_apr_11.pdf

Respecting and Protecting Adults at Risk in Scotland: Legislation and Practice

This is a comprehensive and interactive learning resource, developed in 2011, that supports health and social care workers in practically and appropriately applying the safeguards provided by recent Acts to protect people's rights, and explicitly covers human rights, viz: The Adults with Incapacity (Scotland) Act 2000; the Mental Health (Care and Treatment) (Scotland) Act 2003; and the Adult Support and Protection (Scotland) Act 2007.

http://www.nes.scot.nhs.uk/media/351190/respecting_and_protecting_adults_at_risk_in_scotland_2011.pdf

Targeting mental health nurses pre-registration

The National Framework for Pre-Registration Mental Health Nursing Programmes¹⁷ specifies that 'programmes must have a strong focus on promoting students' ability to practise in a way that emphasises promoting and protecting human rights and addressing the needs of people requiring additional support and protection'. One example of good practice that was highlighted by NES is a module on reflective practice involving people with lived experience and family carers. Glasgow Caledonian University and SRN developed this.

¹⁷ http://www.nes.scot.nhs.uk/media/898307/pre-reg_mh_frame.pdf

Targeting psychiatrists

The UK Royal College of Psychiatrists is responsible for the curriculum development for training psychiatrists. The training for Approved Medical Practitioners¹⁸ includes a focus on Scottish legislative rights.

MWC delivers Excellence in Practice training to mental health professionals and runs annual seminars for Designated Medical Practitioners¹⁹ (DMPs).

Staff induction and training

Examples were provided of organisations providing in-house training and induction for their staff that includes a focus on rights e.g. SAMH's induction for staff includes input on 'Safeguarding the rights of service users' and 'Know your rights', and in the past, it developed bespoke training for its staff - raising awareness and using case studies to consider issues of equalities, diversity and human rights.

There were other examples of training and induction that, while involving rights, did not address these in an explicit manner.

Integrating rights focus into qualifications, registration and review

The Scottish Social Services Council (SSSC), as a professional regulatory and workforce development body, continues to ensure that awareness of human rights and rights-based approaches are built into the qualifications that it regulates, into its codes of practice and into its registration and reviews of individuals.

SSSC and its promotion of human rights among the social services workforce

SSSC is ensuring that a rights-based ethos informs the current review of the Codes of Practice for Social Service workers and employees. These already focus on empowerment and rights, but this focus will be re-emphasised and brought up to date in the revisions. These Codes of Practice apply to around 120,000 workers across social services and hundreds of employers. They provide a regulatory basis on which workers can be challenged if they fail to take a rights-based approach with people who use services and/or their carers.

The Fitness to Practise team investigates concerns about the good character, conduct and competence of a person applying for registration or a person already registered, and takes action where necessary. The SSSC is reviewing these latter processes too in order to ensure that these are rights-based.

¹⁸ An approved medical practitioner is an individual who has been approved under section 22 of the Act by a NHS Board or by the State Hospitals Board for Scotland as having special experience in the diagnosis and treatment of mental disorder. An approved medical practitioner will often be a consultant psychiatrist.

¹⁹ Designated Medical Practitioners are second opinion psychiatrists who provide a safeguard if it is proposed to treat an individual without his/her consent

SSSC continues to promote human rights in its workforce development activities: it ensures that its qualifications, and its education and learning activities, include awareness and practice of rights-based approaches.

It takes the learning from Fitness to Practise cases and uses these to improve practice, including via its education and learning programmes.

SSSC's learning and development activities reach over 190,000 workers in social services in the public, private and third sectors.

The Nursing and Midwifery Council's revised Code of Conduct²⁰ explicitly mentions human rights: it highlights that registered nurses must treat people as individuals and uphold their dignity, and that they respect and uphold people's human rights. Revalidation has to be completed by April 2016. However, uncertainty was expressed about who assesses nurses' human rights competencies and how. Furthermore it was highlighted that currently mental health nurses' CPD does not specifically address human rights.

Additional actions contributing to improved knowledge and understanding in the workforce

Other ways in which organisations were contributing to increased understanding in the workforce were: VOX having members who actively raise awareness about rights with organisations and services; and MWC providing an advice line which takes approximately 3000 calls each year from professionals. Personalisation, self-directed support and welfare reform were also highlighted as areas where organisations were working to promote human rights practices and to tackle the challenges presented by these areas.

Limitations

It would seem that in some cases, while work is described as 'rights-based', it is not always clear what is meant by this. This makes it difficult to establish how well human rights are being addressed, and more specifically - whether or not some rights feature more prominently than others. In some instances, the focus is on legislative rights under, for example, the Mental Health (Care and Treatment) (Scotland) Act 2003 rather than on the wider human rights framework (see further discussion at [Appendix A](#)).

The examples provided relate to specific target groups and in some cases, to rights-based issues subject to mental health legislation. There will, of course, be other target groups and wider rights that are not addressed e.g. lack of clarity was expressed regarding whether and how human rights is addressed in the training and induction of non-clinical auxiliary staff.

Furthermore, in those instances or target groups where there is no professional code, requirement or policy imperative, reach is likely to be subject to the vagaries of individuals' or organisations' interest, motivation and commitment. Where a 'training for trainers' model is used, there may be a risk that aspects of the training are diluted.

²⁰<http://www.nmc.org.uk/standards/code/>

While there were cases of induction programmes that include a focus on rights, these tended not to address rights explicitly. Furthermore, unless a rights focus is explicitly reinforced within organisations and services, there is a risk that this knowledge / awareness will not be maintained.

Systemic issues

In some cases, the lack of specificity about what organisations are doing in relation to promoting rights-based approaches, and where they are being effective, makes it difficult to identify and share best practice, and to identify where the key gaps lie.

There were suggestions that training on rights should be a mandatory requirement for people working in mental health and social care, including general practitioners, and that human resource policies in health boards and associated induction procedures need to embrace human rights explicitly.

There were calls for more opportunities for services and practitioners to engage in more structured / formalised reflection regarding their rights-based practices, and that supervision of staff includes a focus on whether they are consistently adopting rights-based approaches.

Increased self-efficacy & empowerment among service users & carers

The logic model has two closely linked outcomes:

- services are increasingly empowering of service users, and that as a consequence,
- service users have a stronger sense of self-efficacy²¹ and are empowered individually or collectively

In this chapter, we consider these outcomes together.

What is being done

Recovery approaches were valued as being underpinned by empowerment values, and indeed contributing to self-efficacy.

SRN is promoting peer support working, self-management, including Wellness Recovery Action Planning (WRAP), the Scottish Recovery Indicator²² (SRI 2) (www.sri2.net) and the story-sharing website Write to Recovery²³ - a website designed to help people affected by mental health problems on their journey of recovery.

Other organisations pointed to their deployment of peer support workers and the use of other recovery-focused approaches and tools as contributing to self-efficacy and empowerment. For example, several organisations talked of using WRAPs within their services as an approach to service user empowerment, in some cases deploying peer support workers to promote and support the use of these.

WRAP

Wellness Recovery Action Planning (WRAP) is a 'self-management' tool used in many countries around the world to help individuals take more control over their own wellbeing and recovery.

WRAP offers a structured means by which people can maintain wellness and recovery while working to anticipate and reflect on crisis.

WRAP is underpinned by a number of core principles:

- Recovery is possible
- Individuals should take personal responsibility for their own lives and well-being
- It is important to know yourself, to be self-aware
- It is important to believe in and advocate for oneself, and that the support of others is vital

SRN has trained and provides support to over 50 WRAP Facilitators across Scotland.

²¹ Self-efficacy is commonly defined as the belief in one's capabilities to achieve a goal or an outcome.

²² www.sri2.net

²³ www.writetorecovery.net

The empowerment of people with lived experience of mental health and carers is axiomatic to See Me's action to build a social movement. Such empowerment operates at both an individual level and at a community one. For example, See Me has recruited Community Champions – individual volunteers with lived experience who want to take action for change. They receive training and support to develop a specific project to tackle stigma and discrimination in their communities. The emphasis that See Me places on facilitating peer learning further contributes to empowerment of those involved. In addition, See Me is developing a health and social care programme which will have a strong empowerment theme, using voices of lived experience and peer-to-peer learning to change behaviour so that services are increasingly aware of issues of stigma and discrimination and able to address these to empower service users.

Penumbra explicitly details its organisational commitment to all those it supports in a written statement signed by the Chief Executive. This statement is rights-focused and focused on empowerment and recovery.

Penumbra's statement of commitment

Penumbra envisages a society where people with mental health problems expect recovery and are accepted, supported and have the resources to fulfil their potential.

This means:

- We will treat you as an individual with unique needs.
- We will listen to your views.
- We will support you to identify and make informed choices so that you can reach your goals, hopes and aspirations.
- We will make sure you are aware of the opportunities available to you to be involved in your support, the service and Penumbra, and to build your personal and social networks.
- We will challenge any discrimination against you because of your gender, sexual orientation, age, race, disability or for any other reason.
- We will support you with your general health and wellbeing.
- We will treat all information you share with us as confidential within Penumbra and others involved in your support, unless there are legal reasons for us not to.
- We work with an open personal plan policy and you can ask to see your personal plan at any time.
- We will support you to access our complaints procedure if you wish to do so.
- We will support you to access another service if Penumbra cannot meet your needs.
- We will support you on your Recovery journey.

Penumbra also highlighted its work in relation to the development of I.ROC – a tool that helps assess personal outcomes, including empowerment.

Penumbra and the I.ROC

Penumbra seeks to enable the people with whom it works to recover from mental ill health and to fulfill their potential. To assess whether what they do is of value to the people they support, Penumbra has developed an outcome measurement tool, I.ROC (Individual Recovery Outcomes Counter). I.ROC is a facilitated self-assessment questionnaire that measures recovery using the HOPE Model of wellbeing.

- Home - a safe and secure place to live
- Opportunity - to pursue meaningful leisure, recreation, education and work possibilities
- People - as friends, confidantes and supporters
- Empowerment - fully involved in decisions affecting own life

More information is available at <http://www.penumbra.org.uk/wp-content/uploads/2011/06/Introduction-to-I.-ROC.pdf>

VOX empowers service users by giving them a voice, and engaging them in discussions and decisions about the planning and development of mental health and related services, through production of a quarterly newsletter which is free and which allows individual members and group members to have their say. VOX also arranges consultation events and focus groups to make sure its members' views are heard.

Self-management is a core concept in the ALLIANCE's work. Specific projects that are focused on empowering service users and carers include: ALISS – a database of information on local support services, self-management resources and local groups; the Links Worker Programme – a project in 7 GP practices where Community Links Practitioners are posted within practices to signpost patients to community assets for self-management; and the Self-Management Impact Fund which disburses funds to third sector organisations working on new projects for self-management, many with a mental health aspect.

Projects being funded via the ALLIANCE Self-Management Impact Fund

A central feature of all projects funded through the ALLIANCE Self-Management Impact Fund has been the involvement of people with long term conditions in the design, delivery and evaluation of the projects. The next tranche of funding includes:

Mental Health Network (Greater Glasgow) – supporting individuals with mental health conditions to develop high quality advance statements. Individuals will then share their experience of this process and its benefits for self-management

Recovery Across Mental Health (RAMH) – supporting individuals with lived experience of mental health conditions to volunteer as peer mentors to facilitate training sessions on topics on which individuals have expressed a need for more info/support.

NUS Scotland – will do some scoping to find out what students living with mental health conditions would find useful to support their self-management during their studies.

The fund and the projects supported through it have an explicit focus on learning. The insights from these are then shared (See: <http://www.alliance-scotland.org.uk/what-we-do/self-management/self-management-impact-fund/>).

In addition, 'People Powered Health and Wellbeing: shifting the balance of power' (PPHW) is a programme led by the ALLIANCE and funded by the Scottish Government. The central aim of PPHW is that people are able to influence their own health and wellbeing and contribute to the design, delivery and improvement of support and services, including peer support. (This programme is not specific to mental health.)

The Scottish Government's Our Voice initiative, the development of which has been supported by the ALLIANCE and the Scottish Health Council (part of Health Improvement Scotland) is targeting all NHS and social care partnerships to create a streamlined and more consistent system for patient participation ('having their say') in the design of integrated health and social care partnerships, building on the Scottish Health Council Participation Standard. This is not mental health specific.

Self-directed support was highlighted by some organisations as an example of how they are empowering service users and carers.

City of Edinburgh Social Work Services actively support national campaigns (such as those of See Me and SRN) and plan to use peer support workers to promote mental health rights through the use of WRAP and advance statements.

Integrated Joint Boards were seen as providing an opportunity for involving service users and carers, and Penumbra anticipates supporting this.

Limitations

While there are examples of empowering approaches and good practices, it is not evident whether / how these are applied across whole organisations and their client groups.

It is unclear whether and how self-management and self-directed care approaches are being promoted among those populations that are most vulnerable and disempowered, in order to reduce inequalities.

Systemic issues

There is a strengthened policy context for empowerment. For example, Self-directed support potentially offers an important national driver for empowering service users and carers. However, there is a risk that the transformational potential of SDS is not achieved at a time of resource constraints, if alternative provision is not available to make user choice a reality, or individualised budgets become perceived as primarily a rationing tool. There are also particular challenges in relation to mental health

around fluctuating need and supporting people whose decision making ability may be impaired. Addressing this requires sustained commitment from Government and across services.

The Scottish Government is promoting personal outcomes as key to empowering individuals and is currently identifying appropriate tools to measure change in personal outcomes. Doing so may serve to further reinforce the policy context for individuals' empowerment and assist practitioners and services in assessing whether those they support achieve the changes that are important to them as individuals.

While there is policy support for the idea of peer support workers, health boards are not obliged to have people perform this role. Research commissioned by SRN^{24, 25} has indicated that this may be a barrier to their deployment.

More generally, there is a gap between existing rights-based and recovery-oriented policy and people's experiences in practice²⁶.

While there are examples of staff adopting empowering approaches and engaging in good practice, service users (and carers) often feel that the service experience is a disempowering one²⁷.

As indicated previously, there was a view that services and workforces can be risk averse. The research commissioned by SRN uncovered a view that such risk aversion can be a constraining factor for statutory services' employment of peer support workers – a model of support that is considered to be empowering of people with lived experience. Furthermore, among the service users who participated in the Rights for Life workshop, it was felt that services' prioritisation of patient safety could undermine patient privacy. Some of the stakeholders interviewed echoed this view and highlighted services' risk aversion as a key factor in this regard.

²⁴ Gordon, J. (2014) What are decision makers' barriers, facilitators and evidence needs regarding peer support working? <http://www.scottishrecovery.net/SRN/View-category.html>

²⁵ Gordon J and Bradstreet S (2015) *So if we like the idea of peer support workers, why aren't we seeing more?* *World J Psychiatry* 2015 June 22; 5(2): 160-166 <http://www.wjgnet.com/2220-3206/full/v5/i2/160.htm>

²⁶ Some of the challenges for embedding rights-based and recovery oriented approaches have been documented by SRN. See: <http://www.scottishrecovery.net/News-Archive-2014/informing-recovery-approaches-new-srn-research.html>

²⁷ Griesbach D and Gordon J (2013) Individuals' rights in mental health care http://www.mwscot.org.uk/media/129344/rightsinmentalhealth-report-final_apr_2013.pdf

Shared understanding of a quality human rights service and standards

What is being done

National Care Standards

Together with Healthcare Improvement Scotland, the Care inspectorate (CI) is leading the development of the content of the Scottish Government's new human rights-based national standards for health and social care, in conjunction with other stakeholders. It is expected that these will be developed, tested and introduced over the next 12-18 months.

Social Care Services

As the independent scrutiny and improvement body for care services in Scotland, the Care Inspectorate has an annual inspection programme that includes visits to all registered care homes, housing support, secure care accommodation and day care for mental health (as well as other types of needs). The CI is committed to putting human rights at the heart of its inspections, so that people's likes, wishes and choices are respected²⁸ and every inspection includes a focus on participation and rights to liberty through avoiding overly restrictive practices (such as locked doors).

The CI is developing a paper from the perspective of its Health Team. This will be focused on the human rights commitment in its corporate plan and, in turn, will inform and strengthen the CI's functions of regulation, inspection, complaints and reinforcement. This paper will include mental health and learning disabilities.

Older people's Services

Health Improvement Scotland carry out joint inspections with the CI of older people's services, including for mental health. These use a set of quality outcome indicators²⁹ and include statements relating to rights. HIS is also actively exploring opportunities to connect particular areas of work more explicitly to the rights agenda, through the Scottish Patient Safety Programme – Mental Health, and the Our Voice project.

MWC 'visits and monitoring programme'

The MWC has a 'visits and monitoring programme' involving visits to people in a range of care settings and in their own homes. This contributes to not only a shared understanding of human rights services and standards but also to resolving breaches of human rights (a medium term outcome in the logic model).

²⁸ <http://scottishcare.org/news/improving-care-in-scotland-what-the-care-inspectorate-did-in-201314/>

²⁹ These are based on the European Foundation for Quality Management (EFQM). See: <http://www.qualityscotland.co.uk/content/efqm>

MWC visits and investigations

The MWC visits individuals who are in hospital, social care services or prisons and checks that they are aware of their rights and are getting the care and treatment they need, and that this is lawful. This includes regular local visits to individual services alongside a programme of themed visits³⁰, as well as individual visits to people subject to welfare guardianship.

Following a visit, the Commission will write to the service with findings and any recommendations for improvement. Issues of wider concern arising from visits are highlighted in published reports, and in meetings with services. During 2015/16, the Commission will begin to publish individual local visit reports, which should help to promote a shared understanding of the requirements of human rights-based care provision.

The MWC also conducts more detailed casework and investigations in relation to identified poor or unlawful treatment. Major investigations and the reports arising from these are focused on cases which are deemed to offer greatest potential for learning lessons and improving practice across Scotland.

Ancillary activities

Safeguarding patients' rights is at the centre of what the Older People in Acute Hospitals (OPAH) inspections programme was established to achieve. OPAH is not specifically focused on mental health (although it includes delirium and dementia) but its focus on human rights is strong, explicit and tightly operationalised. Healthcare Improvement Scotland, which carries out the OPAH inspections, is committed to ensuring that everyone has access to its inspection reports and makes these publicly available. HIS also produces guidance that is explicitly rights-based.

Over the next five years, there will be an extension of the scope of SSSC registration requirements to include care at home and housing support workers, which means that the Codes of Practice will become enforceable with respect to this large group of workers.

Limitations

The MWC identified challenges in reaching people using non-residential or non-specialist services. To help to address this, it intends in 2016/17 to carry out themed visits to Accident and Emergency departments and to homeless people.

Systemic issues

The MWC identified that there may be a lack of clarity about when to involve the Commission, and as a consequence, there may be some cases that are not brought

³⁰ During 2015/2016, the MWC will visit under its themed visit programme:

- individuals in Intensive Psychiatric Care Units (IPCUs)
- individuals in assessment and treatment units for people with learning disabilities
- individuals in perinatal in-patient services
- individuals with severe and enduring mental illness living in the community

to its attention³¹. (As a mitigating action, MWC monitors the media, although it highlights that some cases may remain un-investigated.)

A diverse range of agencies apply standards to particular settings and to the various professions operating within the mental health and social care system. While there are efforts to consider human rights issues in many of these areas, there is not yet a shared understanding across agencies about human rights standards and the added value of building them into policy and practice e.g. how to balance risk and quality of life considerations and use human rights to provide a common framework of rights and responsibilities for everybody. The patients' rights care pathway that MWC is developing (see page 29) may go some way to addressing this and the new National Care Standards offer significant potential to provide a model of rights-based standards against which services are measured. There remains much work to be done in both consistently embedding human rights in standards across the monitoring and regulation of all settings and professions, and in ensuring those standards are supported by understanding which allows them to be implemented in practice.

Increased clarity was felt to be important for transparency purposes and to provide a stronger basis for assessment and services' accountability.

³¹ Guidance on when to notify the Commission is available at <http://www.mwcscot.org.uk/good-practice/notifying-the-commission/>

Opportunities to strengthen human rights focus in Scottish law and policies are increasingly identified

What is being done

Many of the third sector organisations highlighted their lobbying activities. Examples included:

- SIAA has done research on the impact of advocacy services³² and has used this together with other research, to lobby and campaign for improved access to advocacy including for groups of people whom it feels should have a statutory right to advocacy but currently do not
- SRN is seeking funding for research on implementation of s25-27 of Mental Health Act relating to local authorities' duty to provide care and support services in the community, services to promote wellbeing, and assistance with travel. The research will consider what individuals and local authorities understand about these duties and what they are currently doing to implement them, as well as considering the oversight of these duties.
- SAMH has engaged in concerted lobbying around the Mental Health Bill picking up on specific rights issues such as advance statements, named persons, advocacy and appeals against excessive security, commissioning research and consulting with service users in order that such lobbying is evidence-based.
- VOX lobbies on service users' experiences, and plans work on understanding gaps between policy and practice. VOX will focus on two topics each year to understand in depth the gaps between the rights which exist in practice and the experiences on the ground of its membership.
- The ALLIANCE is pushing for human rights-based approaches across health and social care policy and legislation.
- The joint output by See Me, SRN and VOX of a statement of rights and an action plan from Rights for Life is intended to support the inclusion of mental health human rights in political party manifestos, to increase the explicit presence of human rights in the next mental health strategy, and to further increase the general focus on human rights in mental health policy development generally.

³²SIAA (2014) Advocacy is for the People – Research into the impact of advocacy on the lives of Older People - See more at: [f http://www.siaa.org.uk/2014/advocacy-people-research-impact-advocacy-lives-older-people/](http://www.siaa.org.uk/2014/advocacy-people-research-impact-advocacy-lives-older-people/)

Health and Social Care ALLIANCE – examples of its lobbying activities

Human rights is increasingly one of the key elements of all the ALLIANCE's conversations with politicians and policy responses. The ALLIANCE facilitates conversations/engagement between service providers and duty bearers and meets directly with politicians and civil servants to raise issues of potential retractions of rights and to promote alternatives.

Examples of recent work include:

- National Care Standards – working with the Scottish Government to engage individuals in consultation and highlighting the central importance of human rights
- Health and Social Care integration – sustained lobbying led to human rights being embedded in Principles and Guidance
- Mental Health Bill – ongoing engagement during the parliamentary process, challenging potential retraction in rights of people with mental health problems and carers.

Limitations

There was a feeling that for some issues, member organisations may be better placed to propose amendments to legislation that relate to their area of expertise than is the case with umbrella organisations.

It was felt that at times the effectiveness of lobbying is limited by fragmentation and lack of co-ordination between lobbying and influencing bodies. The formation of the Scottish Mental Health Partnership (SMHP) may help to improve co-ordination. The SMHP was formed following a meeting of mental health organisations in Scotland convened by the Royal College of Psychiatrists in March 2014. It exists to provide a collective voice for organisations with an interest in promoting mental health awareness and improving outcomes for people experiencing mental health issues. Its aims include improving the provision, accessibility and quality mental health services and supports in Scotland, so that these are person centred, rights-based and empowering. Among its current priorities are supporting and encouraging the development of visionary mental health policy, in particular the next mental health strategy for Scotland and developing joint messages and seeking to influence manifestos for forthcoming elections.

There is a widespread lack of awareness of the Convention on the Rights of Persons with Disabilities (CRPD), which sets out a wide-ranging set of measures to promote, protect and ensure the full and equal enjoyment of fundamental freedoms by all persons with disabilities, including mental health issues. This was ratified by the UK as long ago as 2009, but until recently has not featured heavily in discussions about rights-based care. The relevant UN committee is due to review the UK's compliance with the Convention soon, and the Scottish Government is currently working with disability organisations to develop a delivery plan to focus on implementation of the Convention in advance of that review. This provides an opportunity to reflect on how far mental health care is consistent with the CRPD and what can be done to improve compliance.

Systemic issues

Challenges arise in the *implementation* of the Mental Health Act: energy needs to be focused on how to 'give life' to rights. Concerns focused less on the human rights protection offered by legislation and more on the lack of an infrastructure to support implementation of those rights in practice. The low take-up of the right to make an advance statement is an example of this issue, with participants identifying a need to take steps such as making it easier to find the paperwork / guidance for making an advance statement and providing support to individuals to do so. Although human rights should be recognised as, and is, a cross-cutting policy and legislative issue, there was a feeling that there can be a 'silo' mentality.

The General Comment of the UN Committee in relation to Article 12 of the CRPD (equal recognition before the law) has called for a fundamental move away from substituted decision making and forced treatment towards greater respect for the will and preference of people whose decision making ability may be impaired, and more emphasis on supported decision making. This is a difficult and controversial area, and needs careful attention. Work is underway to review the compatibility of the Adults with Incapacity (Scotland) Act 2000 with the CRPD, and a similar process may be required in relation to the Mental Health (Care and Treatment) (Scotland) Act 2003.

Pressures on the workforce have meant that existing provisions in mental health legislation to protect service users' rights are not being discharged in the manner envisaged in the legislation. In particular, there has been a significant reduction in the involvement of mental health officers in emergency detentions, and in providing social circumstances reports for longer term compulsory care.³³

Notwithstanding the issues above, it was felt that the timing for lobbying for rights is opportune in view of the new Mental Health (Scotland) Act 2015 and the implementation which will follow, including the development of regulations; as well as the development of a new mental health strategy.

³³ See MWC Mental Health Act Monitoring Report 2013/14, page 3 [or update with new report if ready in time]

Organisations & services become increasingly effective via learning from service reviews & best experiences and practice

What is being done

The Scottish Patient Safety Programme – Mental Health (led by HIS) aims to systematically reduce harm experienced by people receiving care from mental health services in Scotland, by supporting frontline staff to test, gather real-time data and reliably implement interventions, before implementing them across their NHS board area. Human rights is an overarching theme of the programme and the programme is actively considering ways to further embed rights-based approaches across their work.

Examples were provided by the MWC of specific changes that have been made to services following its monitoring reports e.g. Fife and Glasgow changed their MHO out of hours service as a result. The SSSC identified regulation, including the regulatory process for complaints, contributing to service improvements.

In addition, the Health and Social Care Academy³⁴ hosted by the ALLIANCE aims to support transformational change in health and social care in Scotland. Its focus is explicitly rights-based although not exclusive to mental health. It aims to challenge and change relational aspects of care (its focus is not on organisational change). This involves sharing best practice and joint learning between individuals, the statutory sector and the third sector.

Limitations

Learning does not always translate into changed practice at an organisational level.

Systemic issues

Insights and learning obtained by one organisation are often unknown to other organisations e.g. commissioned research into service users' understanding of their rights and the barriers to these being realised. While sometimes such learning is available through organisations' respective websites, cross-agency awareness of this can nevertheless be low.

In relation to scrutiny and inspection, there has been progress in sharing of intelligence and joint working between bodies such as Healthcare Improvement Scotland, the Care Inspectorate and MWC. This needs to develop further, and include a shared understanding of rights-based scrutiny.

Conversations and learning do not always translate into systemic change. Competing priorities, pressures to be reactive, limited capacity, funding constraints (including short-term funding) and time can be barriers to applying learning to practice.

Organisations need more time and opportunity to engage in reflective practice, introduce changes and monitor their effectiveness.

³⁴ <http://academy.alliance-scotland.org.uk/about-the-academy>

Our reflections and recommendations

Some context and caveats

As indicated at the outset of this report, what we have gathered is a glimpse into some of the work that a sample of organisations in Scotland are doing in relation to increasing the focus on human rights in mental health and social care. In this report, we have summarised what they told us.

However, it is important to realise that this work, and our report, is neither a comprehensive nor a systematic mapping exercise. Rather, it was intended to provide us with insights about some of the key activities that have taken place or that are planned, the changes that these are expected to bring about, and challenges and opportunities for the future in realising people's human rights.

In this section, we present our reflections on what stakeholders and people who use services told us 'in the round', and what we consider to be some of the implications for strengthening a rights-based mental health system.

We identify potential gaps in activity towards achieving the components of a rights-based system as set out in the logic model. We are mindful, however, that the gaps that we identify may not apply equally across the system and that some may have more resonance for some organisations than others. Our reflections are based on the proposition that filling these gaps in activity will help build a system which realises people's rights equitably and on a day-to-day basis.

We offer these reflections within the context of ongoing conversations and with a view to increasing the focus on rights as a key component of mental health care in Scotland as we build on Commitment 5 and move towards a new mental health strategy.

How a focus on rights might be strengthened

Our interviews with organisations identified a large and diverse range of activities that included or involved a focus on human rights. In some of these cases, a focus on human rights was implicit, in other cases explicit. We suggest that wider and more **explicit reference** to the rights-based activities and approaches being taken would help strengthen the focus as required by Commitment 5. As we identified at the outset to this report, a focus on human rights offers a common language and framework to help public bodies (and their partners) stay focused on their key purpose – to improve people's lives. Explicitly identifying, acknowledging and understanding human rights will help strengthen that common purpose.

Many commitments within the Mental Health Strategy 2012-2015 have strong connections to human rights, such as the provision of peer support, carer involvement, stigma and employability. This linkage is not always explicit however, and it would therefore be beneficial if the next mental health strategy mainstreamed human rights across all strands of work. The components of the rights to health (Availability, Accessibility, Acceptability and Quality), the rights set out in the Convention on the Rights of Persons with Disabilities and the PANEL principles all provide frameworks which can be utilised to shape what the strategy aims to achieve. We also see great merit if future strategies were to be aligned with, and

supported by, Scotland's National Action Plan for Human Rights. Doing so would be in line with the Scottish Government's commitment to pursuing a roadmap for the realisation of human rights in Scotland, including in areas of health and social care.

While we have consulted with and involved service users and service user organisations in the process of preparing this report, we believe that there remains much to be learned about the gaps in the realisation of rights from the lived experience of service users.

- 1. We recommend that the next mental health strategy should be explicitly built around a rights-based approach. It should utilise the human rights framework to shape its aims and mainstream human rights across its commitments. In doing so, it should be informed by the lived experience of service users and should align with the aims of Scotland's National Action Plan for Human Rights.**
- 2. We further recommend that the next mental health strategy should include measures to address stigma and discrimination and lack of reasonable accommodation, and improve awareness of the rights of people with mental health issues in mainstream health and social care services. Efforts to combat stigma and discrimination should recognise, maintain and build on existing work to view these as a matter of realising the human rights of those affected by stigma and discrimination.**

We consider that public service reforms are conducive to a strengthened rights-focus: integration of health and social care provides an opportunity to move away from services built around traditional organisational and professional structures towards support which is holistic, person-centred and rights-based. Furthermore, several of the specified outcomes to be delivered by integration are relevant to the need to promote empowerment and self-efficacy³⁵. Nevertheless, we also have concerns that the huge organisational challenges around integration may (inadvertently) draw attention away from continued improvements in mental health services. An explicit rights-based approach to care and support may serve to counteract this, ensuring that health and care services live up to our international obligations to ensure that people with mental health problems are fully included in the community, achieve the highest attainable standard of health, and are protected from exploitation and abuse³⁶.

In making decisions about service design, **integrating human rights with equalities in impact assessment** is an important mechanism for ensuring equality and human rights considerations are embedded into the policies, practices, procedures and priorities of public bodies in Scotland to achieve better outcomes

³⁵ For example, that people are able to look after and improve their own health and wellbeing, and have their dignity respected, and that health and social care services contribute to reducing health inequalities. See The Public Bodies (Joint Working) (National Health and Wellbeing Outcomes) (Scotland) Regulations 2014.

³⁶ Articles 16,19, 25 of Convention on Rights of Persons with Disabilities

and improve performance. SHRC has developed a training resource to help organisations develop integrated assessments³⁷.

- 3. We recommend that the development of policies, practices, procedures and priorities should employ integrated human rights and equality impact assessments. Doing so offers a mechanism for identifying, addressing and embedding equality and human rights considerations.**

With regard to workforce development, there appeared to be a wide range of training initiatives which touched upon human rights to varying degrees. It may be the case that it is not necessary for new training materials to be created, but rather that existing materials can be put to better, more consistent use.

- 4. We recommend a review and subsequent consolidation of existing training initiatives across the mental health workforce against the human rights framework, and with reference to the Convention on the Rights of Persons with Disabilities. This should be used to provide national leadership and direction to all sectors of the health and social care workforce as to how to further embed human rights in workforce development.**

We are aware that the Code of Practice which accompanies the Mental Health (Care and Treatment) (Scotland) Act 2003 is currently under review. This offers a further opportunity to support rights-based practice in implementing the Act.

- 5. We recommend a revision of the Code of Practice accompanying the Mental Health (Care and Treatment)(Scotland) Act 2003 to embed rights-based practice. This should involve explicit connections to human rights principles and to the human rights framework.**

The low uptake of advance statements was identified by the people we spoke to, and specific concerns were expressed regarding the opportunities that mental health officers – an already stretched resource - have to promote rights issues generally including the specific issue of advance statements. Wider deployment of (paid) peer support workers could be *part* of the solution to meeting this

- 6. We recommend that the Scottish Government should issue a Chief Executive letter to Health Boards setting out clearly the expectations on Boards to promote the wider use of advance statements, and should consider what national guidance and support should be made available to support this. This should reflect the new duties in section 26 of the Mental Health (Scotland) Act 2015, drawing on the experience of existing projects seeking to build such support and the work of the MWC-led group on advance statements.**

While advance statements offer an avenue for supported decision-making, there is a need to consider advance and supported decision-making in relation to care and treatment more widely (not just in crisis care). The Convention on the Rights of Persons with Disabilities presents a particular challenge and impetus for action in

³⁷ <http://www.scottishhumanrights.com/eqhria>

this area. In particular, Article 12 requires that a person must have access to support to make decisions which respect their will and preferences, where this is needed. While some organisations mentioned this as a challenge that needs to be addressed, there is clearly both theoretical and practical work to be done.

7. ***We recommend the Scottish Government should coordinate interagency discussion and action at a national level to explore issues of capacity and supported decision-making. Efforts should be focused on strengthening existing forms of supported decision making and identifying how further models can be developed which reflect the Scottish legal and service context, and respond to the implications of the UN Convention on the Rights of Persons with Disabilities.***

Challenges were identified in reaching people *prior* to crisis in order that they can understand their rights. The forthcoming SNAP³⁸ campaign on human rights towards the end of 2015 provides one route to this. It also presents an ideal opportunity for additional and complementary ***communications on rights that are specific to mental health***. Key national organisations may wish to build on this campaign.

8. ***We recommend that there should be further exploration of ways for service users to be provided with consistent, reliable and accessible information on rights, prior to and during crisis points, with opportunities for them to be reiterated at key points during care and treatment. The manner in which this should be provided should be informed by the lived experience of service users. The human rights care pathway to be developed by the MWC and the statement of rights that will be produced by SRN, See Me and VOX offer useful starting points.***

While we heard many examples of work, our interviews did not always allow us the time and opportunity to hear in detail what organisations are actually achieving i.e. the changes that are effected as a consequence of their activities, and in whom. In some cases, organisations might have been able to point to such evidence but we suspect that this may not always have been possible. Such evidence is, however, key to an ongoing process of learning and improvement. In particular, it would be useful to better understand (and evidence) who we are reaching, and not just whether changes are being produced in the short-term (such as improved knowledge) but whether changes are being sustained over time, and translating into the longer term outcomes that we intend and as indicated in the logic model. Of course, there will be limits to just how much can be evaluated, but we feel that an improved focus on rights would be well-served by ***proportionate monitoring and evaluation***. We consider that this should include monitoring and evaluation of the extent to which integrated services are promoting service user empowerment and self-efficacy, and are doing so effectively.

While we heard examples of research and evaluation (and indeed know of other examples that were not mentioned), the reports on these are not always widely known despite there being interest in the issues that they address. This is not to say that they are not made available: they often are. There would be obvious merit in an

³⁸ SHRC working in partnership with Scottish Government and members of the Better Culture Action Group

improved infrastructure, perhaps a one-stop-portal and associated social media messaging, for **sharing emerging evidence** on key pieces of research and evaluation that apply to human rights across mental health and social care e.g. on barriers to realising the right to an advance statement, what works well etc. In addition, a portal of this nature might usefully include details of the legislative context for human rights, new debates and proposals, best practice and the roles and responsibilities of different agencies.

- 9. We recommend the development of an online portal bringing together and making accessible rights-based materials, evidence and best practice. The content of this portal should be quality-controlled and curated to ensure that it remains focussed on content which is explicitly rights-based.**

As indicated above, we heard examples of work in relation to specific rights, such as the right to an advance statement, and other rights under the Mental Health Act. We also heard of activities that were less explicit about which particular rights were being addressed and the precise changes that they expected to be achieved as a direct consequence. Finally, we heard of programmes for which a focus on rights was inherent but not explicit. In view of this range, we consider that tighter specification of precisely which particular rights are being addressed by individual organisations, programmes and initiatives would help focus service improvement as well as aid transparency and accountability. Doing so would also offer the potential to identify whether there are any specific rights that are not being so well addressed across Scotland.

Narrowing inequalities is a cross-cutting issue for Scottish policies and services. However, from our interviews, it was not always clear whether and how some initiatives were proactively **targeting the most vulnerable** sectors and groups in society. Thus, while there were examples of information being **made available** to service users or **opportunities** for service user participation, we wonder whether more consideration needs to be given to how we reach those who are not already 'switched on' to having rights and those who are less likely to access sources of information or support.

There have been calls for more clarity on what a human rights-respecting pathway should look like. The human rights care pathway to be developed by MWC and colleagues is intended to help address this.

There will be an issue too about not just what a human rights care pathway looks like, but also how this is communicated – not only to those who are involved in service design and delivery but to service users and carers.

In developing these resources, and indeed others, there will be inevitable challenges in not only 'simplifying the complex', but in establishing a **shared language**. In this respect, we note comments that much of the current language may not be comprehensible or appropriate to lay people. This is an issue that will need to be addressed.

Challenges were raised with regard to upholding people's rights to safety while at the same time meeting their (and other patients') wider rights. There will be no easy solutions to this, but these are debates that need to be aired with a focus on identifying how such challenges might be resolved. In these areas, a full understanding of the human rights framework and, in particular, the proportionality principle can assist in balancing risk and quality of life considerations and can provide a common framework for rights and responsibilities for everybody.

There were concerns regarding the significant demands on MHO services to deliver on, and fulfil, the expectations of the Mental Health (Care and Treatment) (Scotland) Act 2003 and the Adults with Incapacity (Scotland) Act 2000. We consider that there is an outstanding need to address this pressure.

It was widely acknowledged that advocacy provision is insufficient and that it can often be limited to people under compulsory treatment orders. This was never the intention when a right to advocacy was introduced in the Mental Health (Care and Treatment) (Scotland) Act 2003, and the new responsibilities on the NHS and local authorities in the 2015 Act are welcome. We are in little doubt that an increased focus on rights will require **improved access to and quality of advocacy**. Meeting this will require both increased provision and a robust framework to provide ongoing individual evaluation of advocacy organisations to ensure quality is achieved and maintained. The quality assurance project being undertaken by SIAA offers an opportunity to build such a framework.

The approaches and tools used in relation to recovery were seen to offer a route to supporting individuals to fulfil some of their rights (such as participation). However, it is well known that despite the policy focus on recovery, the realisation of recovery is not universally felt as services vary in the extent of their recovery practices. In view of the contribution that recovery-based approaches can make to the realisation of rights, we see enormous value in services considering how **recovery focused** they are, and following through on opportunities for improvement. The Scottish Recovery Index (SRI 2) developed by SRN provides a practical tool to help them with this.

As indicated earlier, we heard concerns regarding the likely success in meeting the human rights of some of the most vulnerable sectors of society. Within this context, it is notable that conversations did not generally extend to forensic services. More consideration needs to be given to **progress and challenges in meeting the rights of people being treated under forensic services**, including those under community treatment orders.

In order to build a rights-based system, it is important that intentions to realise human rights are backed up by accountability which provides both effective monitoring and effective remedies when rights are not realised. Issues were identified in this area, including people knowing where to seek redress, having support to do so (whether advocacy or legal support) and legal and complaints mechanisms being accessible and leading to meaningful redress. We heard some discussion of these issues, however, we believe that this is an area where further consideration from a service user perspective would further illuminate the issues and help inform action.

We acknowledge that we have obtained just a snapshot of some of the activities and challenges faced by services. However, we feel that this has provided a more informed perspective on some of the issues that we collectively face in increasing the focus on human rights in mental health and social care, and an indication of some of the steps we can take to address the gaps identified.

We hope that this report will serve to further stimulate ideas, discussion and improved outcomes.

Appendix A: The legislative context for human rights

A human rights-based approach is grounded in international human rights laws to which the UK has voluntarily agreed to be legally bound. This includes rights under the European Convention on Human Rights³⁹, such as the right to life, to not be subjected to torture or inhuman or degrading treatment, to liberty and security, to a fair trial, the right to private and family life⁴⁰. It also includes rights under international treaties to which the UK is legally bound, such as the right to equal recognition before the law⁴¹.

The international human rights framework also includes rights towards which we must show progress over time, such as the right to the highest attainable standard of physical and mental health⁴² and the right to live independently and be included in the community⁴³.

Of particular significance to mental health is the UN Convention on the Rights of Persons with Disabilities, which sets out the rights to which disabled people, including those with mental health needs, are entitled. It does not create new rights but rather sets out the steps that must be taken to remove the barriers that disabled people face in accessing their rights on an equal basis with others. This includes rights with significant and increasingly important implications for the mental health system, such as the right to equal recognition before the law⁴⁴, which requires that a person must always be supported to make decisions which respect their will and preferences.

These are just a few of the most relevant rights within the broader framework, all of which a rights-based mental health system would seek to respect, protect and fulfil.

It is important to note that this is wider than the legislative rights afforded under legislation such as the Mental Health (Care and Treatment) (Scotland) Act 2003 or the Adults with Incapacity (Scotland) Act 2000. Many of the rights afforded under these Acts are based on, and underpinned by, human rights principles. For example, the right to liberty means that you must be able to appeal your detention in hospital and the right to make an advance statement is an important form of supported decision-making which protects your right to private and family life and to equal recognition before the law. The human rights framework provides, however, for a broader range of rights than those which have been specifically provided for in mental health legislation. By law all legislation in Scotland must be read and given effect to in a way which is compatible with the European Convention rights outlined above and so all legislation must be looked at and interpreted through a human rights lens.

³⁹ The European Convention on Human Rights became part of Scots law in 1998. The Human Rights Act 1998 makes it unlawful for Scottish public authorities to act, or fail to act, in a way that is incompatible with the European Convention on Human Rights.

⁴⁰ Articles 2, 3, 5, 6 and 8 ECHR

⁴¹ Article 12 UN Convention on the Rights of Persons with Disabilities (CRPD)

⁴² Article 12 International Covenant on Economic, Social and Cultural Rights

⁴³ Article 19 UNCRPD

⁴⁴ Article 12 UN Convention on the Rights of Persons with Disabilities

While at a UK level, there has been some debate about the possibility of repealing the Human Rights Act (1998), within Scotland there is Scottish Government and cross-party support to promote human rights. Furthermore, Scotland has its own National Action Plan for Human Rights (SNAP). This includes a section that focuses on health and social care.

Appendix B: Partners and stakeholders

Steering group

Beth Hamilton, Scottish Government

Cathy Asante, Scottish Human Rights Commission

Colin McKay, Mental Welfare Commission

Anne Birch, Mental Welfare Commission

Alison McRae, Mental Welfare Commission (to February 2015)

Kate Fearnley, Mental Welfare Commission (from February 2015)

Organisations represented at the meetings and interviews in 2015

Health Improvement Scotland

Health and Social Care Alliance Scotland

Care Inspectorate

Mental Health Nurses Forum Scotland

Mental Welfare Commission for Scotland

NHS Education for Scotland

NHS Lanarkshire Health Board

Penumbra

Scottish Association for Mental Health

Scottish Human Rights Commission

Scottish Independent Advocacy Alliance

Scottish Recovery Network

Scottish Social Services Council

See Me

City of Edinburgh Council

Royal College of Psychiatrists

Voices of eXperience

Appendix C: Glossary of acronyms

Acronyms for organisations contributing to this report	
The ALLIANCE	Health and Social Care Alliance Scotland
CI	Care Inspectorate
CEC SWS	City of Edinburgh Council Social Work Services
MHN	Mental Health Network (Greater Glasgow)
MHNFS	Mental Health Nurses Forum Scotland
MWC	The Mental Welfare Commission for Scotland
NES	NHS Education for Scotland
NHS Lan	NHS Lanarkshire health board.
SAMH	The Scottish Association for Mental Health
SHRC	Scottish Human Rights Commission
SIAA	Scottish Independent Advocacy Alliance
SSSC	Scottish Social Services Council
RCP	Royal College of Psychiatrists
VOX	Voices of eXperience
Human Rights organisations	
BIHR	British Institute of Human Rights
ECHR	European Convention on Human Rights 1950
EHRC	Equality and Human Rights Commission
SHRC	Scottish Human Rights Commission
Legislation	
	Human Rights Act 1998
	Scotland Act 1998
	Patients' Rights Scotland Act 2011
United Nations Treaties	
ICERD	International Covenant on the Elimination of All Forms of Racial Discrimination
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICCPR	International Covenant on Civil and Political Rights
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
CAT	Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment
CRC	Convention on the Rights of the Child
ICRPD	Convention on the Rights of Persons with Disabilities
Miscellaneous	
CPD	Continuous Professional Development
ESC	Essential Shared Capabilities
EFQM	European Foundation for Quality Management
EQIA	Equality Impact Assessment
HR	Human Rights
I.ROC	Individual Recovery Outcomes Counter
RfL	Rights for Life event
SDS	Self Directed Support
SNAP	Scotland's National Action Plan for Human Rights
SPSP	Scottish Patient Safety Programme
SRI2	Scottish Recovery Indicator 2

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www.aliss.org

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ALLIANCE Improving links in primary care.

www.alliance-scotland.org.uk/what-we-do/our-work/improving-links-in-primary-care

ALLIANCE Stronger Voice

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ALLIANCE People powered health and well being

www.alliance-scotland.org.uk/what-we-do/our-work/people-powered-health-and-wellbeing

ALLIANCE Health & Social Care Academy

academy.alliance-scotland.org.uk

Care Inspectorate The Hub

hub.careinspectorate.com

Care Inspectorate Policy Portal: Human Rights

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Penumbra: Individual Recovery Outcomes Counter (I.ROC)
www.penumbra.org.uk/innovation/personalised-services

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www.scottishhumanrights.com/careaboutrights

Scottish Human Rights Commission (SHRC) Human Rights Based Approach
www.scottishhumanrights.com/humanrights/humanrightsbasedapproach

Scottish Human Rights Commission (SHRC) SNAP - Scotland's National Action Plan for Human Rights
www.scottishhumanrights.com/actionplan

Scottish Recovery Indicator 2
www.sri2.net

Scottish Patient Safety Programme: Mental Health
www.scottishpatientsafetyprogramme.scot.nhs.uk/programmes/mental-health

SAMH (The Scottish Association for Mental Health) Know Your Rights
www.samh.org.uk/our-work/public-affairs/know-your-rights

SAMH (The Scottish Association for Mental Health) Quick Guide to Your Rights
www.samh.org.uk/media/219658/know_your_rights.pdf

Scottish Health Council: Participation Standard
www.scottishhealthcouncil.org/patient_public_participation/participation_standard/participation_standard.aspx#.VaPQX7twaiq

Scottish Independent Advocacy Alliance (SIAA) Quality Assurance
www.siaa.org.uk/campaignsprojects

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www.siaa.org.uk/wp-content/uploads/2014/11/Advocacy-Map-141114.pdf

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www.sssc.uk.com/fitness-to-practise/what-is-fitness-to-practise/a-guide-to-fitness-to-practise

See Me: End mental health discrimination
www.seemescotland.org

SeeMe: Community Champions
www.seemescotland.org/our-movement-for-change/supporters/champions

SRN (Scottish Recovery Network): WRAP Wellness Recovery Action Planning
www.scottishrecovery.net/WRAP/wellness-recovery-actions-planning.html

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