



Human rights in health and social care – putting it into practice

CASE STUDIES FROM SCOTLAND



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Human rights in health and social care

Respect for the fundamental dignity of each and every person lies at the heart of human rights, as do the principles of equality and individual autonomy. These values, among others, are also important measures of success for health and social care services in Scotland.

Grounded in the 1948 Universal Declaration of Human Rights, a comprehensive set of international human rights has since been developed, established and adopted around the world. Some of these have been incorporated directly into Scotland's domestic laws. Others are set out in international legal obligations that the Scottish Government has a duty to implement.

Realising these principles in practice – making human rights a reality in everyday life for people using health and social care – can sometimes seem more complicated than it really is. As part of Scotland's National Action Plan for Human Rights (SNAP), the Scottish Human Rights Commission, the Health and Social Care Alliance and NHS Health Scotland have developed this guide to help organisations learn from others who have put human rights into practice.

The guide gives case study examples, drawn from Scotland's voluntary and community sectors, of a human rights based approach to the design and delivery of a range of services including advocacy, dementia care, mental health and abuse prevention. It shows how simple and effective steps can turn human rights principles into practical improvements in the quality of health and social care services.

As the integration of health and social care in Scotland becomes a reality and as Scotland continues to work towards tackling health inequalities, a human rights based approach offers an important mechanism for improving the quality of outcomes for people, whoever they are and wherever they live. We hope this guide will help more organisations embed human rights into the design and delivery of their services. Short films showing each case study in action are available online at **www.healthandsocialcare-snap.com/case-studies**

We would like to thank all of the people and organisations who have contributed their time and shared their experiences to help produce this guide and, in particular, Sarah McDermott of the Health and Social Care Alliance.



Participation

Accountability

Non-discrimination

Empowerment

Legality

A human rights based approach: PANEL principles

Taking a human rights based approach is about using international human rights standards to ensure that people's human rights are put at the very centre of policies and practice.

A human rights based approach empowers people to know and claim their rights. It increases the ability of organisations, public bodies and businesses to fulfil their human rights obligations. It also creates solid accountability so people can seek remedies when their rights are violated.

The **PANEL** principles are one way of breaking down what a human rights based approach means in practice.

PANEL stands for **P**articipation, **A**ccountability, **N**on-Discrimination and Equality, **E**mpowerment and **L**egality.

Participation

People should be involved in decisions that affect their rights.

Accountability

There should be monitoring of how people's rights are being affected, as well as remedies when things go wrong.

Non-Discrimination and Equality

All forms of discrimination must be prohibited, prevented and eliminated. People who face the biggest barriers to realising their rights should be prioritised.

Empowerment

Everyone should understand their rights, and be fully supported to take part in developing policy and practices which affect their lives.

Legality

Approaches should be grounded in the legal rights that are set out in domestic and international laws.



PANEL: in people's own words

Participation

“We felt it was essential to involve parents and carers and the wider community in our project. So we actively seek out young people and their parents and carers within the community, delivering the sessions in faith institutions, youth groups and community groups.”

ANELA ANWAR, ROSHNI

Accountability

“Having knowledge of human rights enables you to understand more clearly what the duties are in relation to local authorities and health boards – how you should be treated, and what you should expect. It also gives you recourse where that isn't happening. That doesn't necessarily mean recourse through the courts but it means that organisations like the Advocacy Project are able to frame issues in light of human rights and take them forward to achieve positive outcomes for people.”

LAURA BOGUCKI, THE ADVOCACY PROJECT

Non-discrimination and Equality

“The more I listen to human rights discussion, the more I realise it's about what we do. It's about talking; it's about having a voice; it's about challenging discrimination; challenging the wrong attitudes towards people with mental health problems.”

GRAHAM MORGAN, HUG (ACTION FOR MENTAL HEALTH)

Empowerment

“For someone with dementia, it is so important to empower them to know that they have a right to be involved in decisions about their care, that someone should be accountable for that care and to tell unpaid carers and families that you have those rights. We really have to get that message out. Because if people don't know what their rights are then they can't claim them.”

IRENE OLDFATHER, DEMENTIA CARER VOICES

Legality

“Using the language of human rights helps people to understand that what we do isn't because we're being nice, or giving an added extra, it's actually our duty to help people have their human rights fulfilled.”

SAM SMITH, C-CHANGE SCOTLAND

CASE STUDY ONE: DEMENTIA CARER VOICES

Introduction

The policy framework around dementia is explicitly based on upholding and promoting the human rights of people with dementia. The Charter of Rights for People with Dementia and their Carers in Scotland, published in 2009, uses the PANEL approach to emphasise the applicability of human rights to people with dementia and their carers. Following this, Scotland embedded the Charter to ensure that the systems and structures of care and support focus on upholding and promoting human rights.

The Dementia Carer Voices project, managed by the ALLIANCE, was set up in early 2013 to assist in bridging the gap between the aims of the Dementia Strategy and the experiences of people living with dementia. The project is working to ensure that people are aware of their rights and are empowered to know that their views are taken seriously and are at the heart of planning services. The experiences of those affected by dementia are used to inform policy, through engagement with a wide range of stakeholders such as Scottish Ministers and the Scottish Parliament. Their experiences also directly influence those who deliver health and social care services. The project engages with health and social care professionals and students to emphasise the need to put people at the centre of services and to identify opportunities to strengthen the protection of the human rights of people with dementia in health and social care settings. These include advancing the benefits of embedding a human rights based approach in management culture and staff training and highlighting through the carer perspective issues of staff turnover and time constraints.

What they say

“I used to think that human rights was a little bit of an airy fairy concept. But I’ve come to realise that actually it’s about empowering people. It’s about dignity and respect. We came up with a Charter of Rights for people with dementia and their carers. That’s a fantastic example of how you can embed rights into a policy framework because we took that charter and embedded it into the National Dementia Strategy. It’s a very simple approach to human rights based on the PANEL approach.”

IRENE OLDFATHER, DEMENTIA CARER VOICES



“For me human rights is about really deeply listening to people, to what matters to them and for them and it has to be a very person-centred approach. Human rights is a massive big thing but we need to chunk it down into individual needs. We need to work side by side and encourage staff who work in care homes who are faced with challenges day in and day out.”

CAROLINE BROWN, DEMENTIA CARER



Putting PANEL into practice

Participation

The project involves a range of stakeholders across communities to raise awareness of the dementia journey and encourages carers to reflect on and share their experiences. To date, an online carer survey and an analysis of carers letters has captured key messages of the importance of listening to and involving carers at every step of the dementia journey.

Accountability

In capturing information from carers and sharing it with Scottish Ministers and other key stakeholders such as the Scottish Public Services Ombudsman and the Care Inspectorate, the project aims to ensure a strong voice for those who use services. The 'You Can Make a Difference' campaign calls upon health and social care professionals to reflect on the lived experience of people affected by dementia, and identify actions that they can take away and apply to their everyday practice to make a difference. The pledges are catalogued and published online, so that professionals can learn from each other. This also empowers carers themselves to know that their voices are being listened to.

Non-discrimination and Equality

The project uses social media, hosts events, delivers workshops and goes round the country to ensure that as many people as possible are aware of the campaign and their views are put forward. The project works with a broad reach of partners across the sector including Alzheimer Scotland and Focus on Dementia to ensure views are gathered from a diverse range of people.

Empowerment

The project works to empower carers by raising awareness of their rights and the level of services and support to which they are entitled, and provides signposting to organisations which can provide support where these expectations are not met. Through the 'You Can Make a Difference' campaign, and presenting the views of carers, the power of the lived experience of carers is harnessed to influence health and social care policy, culture and practice.

Legality

The project follows on from the Charter of Rights for People with Dementia and their carers, which is explicitly based on upholding and promoting the human rights of people with dementia and their carers. It applies universal human rights, strengthened by the rights identified in the United Nations Convention on the Rights of Persons with Disabilities as legally enforceable entitlements underpinning the situation of people affected by dementia.



CASE STUDY TWO: HUG (action for mental health)

Introduction

HUG is a collective advocacy group representing the interests of users of mental health services across the Highlands. HUG believes that people with direct experience of mental health problems have an expertise that cannot be found elsewhere. Collective advocacy can harness this expertise and use it to influence the ways in which services are developed and run, to educate professionals and the public, and to also empower and influence individual members' lives.

HUG's Communications Project aims to reduce stigma and raise awareness and understanding about the lives and experiences of users of mental health services.

One of its key activities is delivering training to mental health officers, who are closely involved in the process of detaining users in hospital and ensuring they receive treatment even when they do not want it. HUG uses discussions about human rights to open up a dialogue between these different perspectives, which might otherwise be in conflict. The training takes into account a broad spectrum of views, from those who disagree with the basic idea of compulsory treatment to those who think it saves lives. It harnesses the personal and often very difficult experiences of those who use mental health services to stimulate debate about human rights and to find ways of interacting that break down barriers between different points of view.

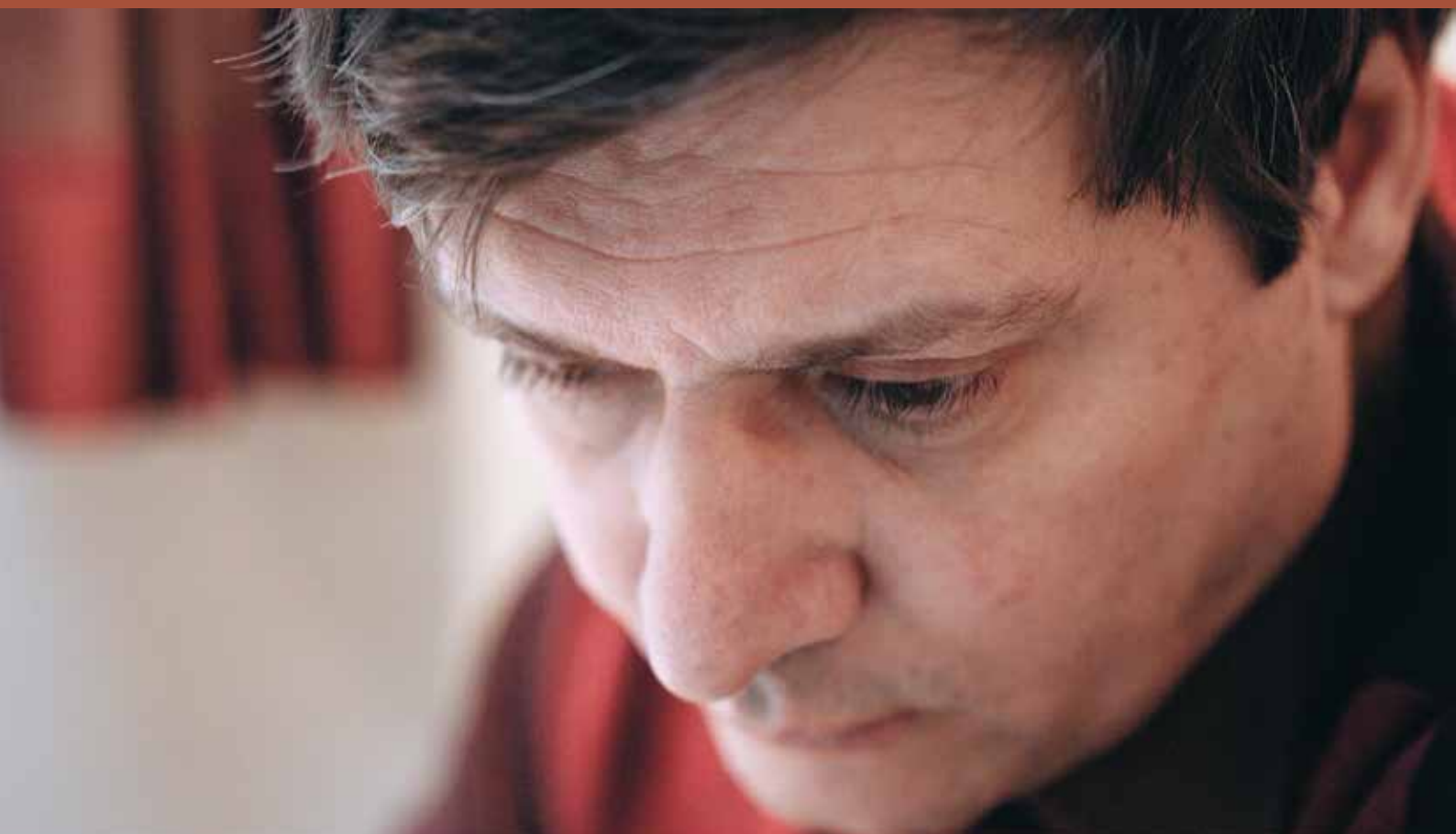
What they say

“We've been working with mental health officers for the past decade. We go into a room with them and they're the people who have often detained us personally. We're the people who've been detained and we start a dialogue. We start talking to each other. We start learning from each other. We tell our stories and they tell their thoughts too. And by speaking together and learning our different perspectives, they can do their job better. We can feel some sense of liberation at having helped them understand us and telling them our story. Through that, people value us. They see us as people rather than people who they are doing a job with.”

GRAHAM MORGAN, HUG (ACTION FOR MENTAL HEALTH)

“My initial reaction to human rights is of demonstrations and legal courtrooms and things like that. But the more I listen to human rights discussions, I realise it’s about what we do. It’s about talking; it’s about having a voice; it’s about challenging discrimination; challenging attitudes.”

GRAHAM MORGAN, HUG (ACTION FOR MENTAL HEALTH)





Putting PANEL into practice

Participation

HUG harnesses the experiences of its members, whose rights are affected by mental health services, to shape the development and delivery of services.

Accountability

The training of mental health officers provides for direct engagement with those who are personally responsible for decisions which affect the fundamental human rights of those HUG represents.

Non-discrimination and Equality

HUG seeks to ensure that having a mental health problem does not present a barrier to its users' involvement. Attempts are always made to communicate in plain English. Where a member is not well enough to communicate with professionals they are encouraged to participate in other ways until they are well enough for a greater level of involvement. Where a member's illness does not interfere with the HUG ground rules, people would be expected to adapt to the problems that the person is facing.

Empowerment

By engaging in discussions centred around their human rights, members are empowered to know and understand their rights and to participate in debates which look at the complexities surrounding those rights. They are also empowered to use their experiences to influence the practices which affect their lives.

Legality

HUG advocate in relation to issues affecting human rights protected under the European Convention on Human Rights and other international human rights obligations, such as the right to liberty, the right to private and family life and the right to freedom from inhuman and degrading treatment.

CASE STUDY THREE: C-CHANGE SCOTLAND

Introduction

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

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

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

What they say

“Human rights is a framework that provides a steely core to what we do. It stops us from considering that people’s ability to have their rights realised is an option or a gift... We’re manifesting their rights, we’re supporting them to do what everyone else has the right to do and it’s defined in law.”

“The [UN Human Rights] Conventions inspire me; in those documents is our better selves and that’s why they’re a guide for this organisation and for me personally.”

SAM SMITH, C-CHANGE SCOTLAND

“I knew I had human rights but I didn’t know I had the same human rights as anybody else.”

DAVID HARVEY, C-CHANGE SCOTLAND CLIENT



Putting PANEL into practice

Participation

Individuals choose who works for them and continuously review their services to make sure they meet their needs. C-Change Scotland actively involves families, friends and communities as the foundation for support. Service users are also fundamental to continuous review of the work of the organisation as a whole.

Accountability

C-Change Scotland has a flat and accessible management structure. The Improvement Council, made up solely of service users, provides a direct link to the Board of Directors so that the organisation is accountable to those it works for.

Non-discrimination and Equality

C-Change Scotland ensures that everyone is able to exercise choice in their services regardless of their level of support needs, their personal circumstances or their background. A flexible approach to support services means that those who might be marginalised by a more rigid service are able to access their rights on the same basis as others.

Empowerment

Power and control remain with or as close to the individual being supported as possible to ensure that they direct their own support. The value of their lived experience, their opinions and values, are central to designing their own services and the services of the organisation.

Legality

C-Change Scotland uses the legal framework of international human rights standards to guide the services it provides and the ethos underpinning the organisation. It grounds its approach in a recognition that it exists to assist the people it works with to access their rights – to maintain family relationships, to live independently – on the same basis as others.

“Human rights is a framework that provides a steely core to what we do. It stops us from considering that people’s ability to have their rights realised is an option or a gift... We’re manifesting their rights, we’re supporting them to do what everyone else has the right to do and it’s defined in law.”

SAM SMITH, C-CHANGE SCOTLAND





CASE STUDY FOUR: THE ADVOCACY PROJECT

Introduction

The Advocacy Project provides independent advocates for people with mental health problems, older people and people with a physical disability. It aspires to make human rights central to its work, to enhance the rights and strengthen the voices of marginalised and vulnerable people.

The project provides human rights training to all its advocacy workers. Through induction training and ongoing workshops, workers learn to use the language of human rights in their work and to challenge breaches of human rights for their clients. The project holds a regular forum where workers can discuss human rights issues and work through the human rights implications of situations they are dealing with. They also carry out a rolling programme of awareness raising about advocacy and human rights.

What they say

“Having knowledge of human rights enables you to understand more clearly what the duties are in relation to local authorities, health boards etc – how you should be treated and what you should expect. It also gives you recourse where that isn’t happening. That doesn’t necessarily mean recourse through the courts but it means that organisations like the Advocacy Project are able to frame it in light of human rights to take it forward and achieve positive outcomes for people.”

LAURA BOGUCKI, THE ADVOCACY PROJECT

“I had to go into hospital for operations and because I’m a small person, they did not have the necessary equipment like a commode, a zimmer and other items. No matter what size you are, you should have that equipment there for you. Human rights mean you are a person, that you are just as equal, whether you are small or otherwise.”

PATRICIA RYAN, ADVOCACY PROJECT SERVICE USER

“Human rights mean you are a person, that you are just as equal, whether you are small or otherwise.”

PATRICIA RYAN, ADVOCACY PROJECT SERVICE USER





Putting PANEL into practice

Participation

The provision of advocacy services is fundamentally about helping those who may require help in speaking for themselves to participate in decisions that affect them, whether they be about healthcare, social activities or legal processes.

Accountability

Advocacy workers help their clients to access accountability mechanisms such as complaints processes, courts and tribunals. The Advocacy Project hold regular workers' forums to allow them to discuss human rights issues which arise and review the work they are doing.

Non-discrimination and Equality

The project has identified groups who face particular barriers to realising their rights, such as the minority ethnic population, who are facing a rise in admissions. The project seeks to prioritise those groups for further engagement.

Empowerment

Advocacy workers help their clients to know and understand their rights, particularly during legal processes such as detention in hospital or the appointment of a guardian to make decisions on a client's behalf. They do not make decisions on behalf of their clients but rather seek to assist their clients to form their own views and have those views heard.

Legality

The project chose to thread human rights throughout their work in recognition of the fact that the situations they deal with on a day to day basis are grounded in legally enforceable human rights, such as the right to private and family life, the right to liberty and the right to a fair trial. Making the explicit connection to human rights helps back up representations made on behalf of clients.

CASE STUDY FIVE: CONVENTION ON THE RIGHTS OF RESIDENTS IN CARE HOMES (SCOTTISH CARE)

Introduction

The Convention on the Rights of Residents in Care Homes for Adults and Older People is a project undertaken by Scottish Care. Scottish Care is a representative body of the largest group of independent providers of health and social care across Scotland, delivering residential care, day care, care at home and housing support. They worked with residents and staff of care homes to develop a document they named a “Convention” collectively expressing their views of the basic minimum rights that people living in a care home should expect to achieve.

Scottish Care held workshops with care home residents and staff, who identified what rights they believe need to be promoted and protected to make sure their time in care is empowering, dignified and fulfilling. They drew these rights into a comprehensive statement of 16 articles. The “Convention” was launched on 20 November 2015.

The “Convention” is available to sign up to by partners in the Scottish Government, local authorities and providers across Scotland. This enables them to express their support for its terms and their willingness to ensure that funding, resources and supports are in place to enable everyone living in residential care to exercise their fundamental rights. In turn, that enables people living in care homes to live life to the fullest and achieve what is important to them.



What they say

“Human rights give you a really strong starting point for what you’re trying to do if you’re delivering services. It’s almost like the ground rules that you can work from. Situations occur and if a staff member feels like they don’t know how to address that or where to start with resolving that issue then going back to human rights principles, thinking about those and thinking “Ok, what’s important to this person here? Have we made sure that the person has been heard and they’ve made their own choice?” If all of these things are there, then you know you’re doing things the right way.”

CARLYN MILLER, SCOTTISH CARE





“My idea of human rights has quite changed. We felt the scheme involved us, as well as outsiders; that was how it changed. Human rights... you think it’s something outside here but it’s not; it’s us as well as everybody else. We’ve got our human rights as much as anybody else.”

MARGARET MCALLISTER, CARE HOME RESIDENT



Putting PANEL into practice

Participation

The development of the Convention was driven by residents and staff of care homes. Workshops were held in a local community centre and participants were asked open questions such as “What’s good/not so good about living in a care home?”, “What do you consider good care and support?” and “What rights are important and how would you describe them?”. Their input was used to draft the Convention and their feedback was gathered to make sure everyone approved the final document.

Accountability

The Sign Up method asks organisations, councils and individuals to sign up and pledge to adhere to the Convention and embed human rights in practice. A certificate can be displayed to further raise awareness and accountability for staff in adhering to these rights in practice.

Non-discrimination and Equality

A key theme in developing the Convention was that an individual’s rights are not diminished when they move into a care home. For example, the Convention highlights issues such as equal access to the community for residents taking part in religious activities and community events.

Empowerment

Awareness of human rights was raised through the process of running workshops and discussing issues with residents and staff through a human rights lens. The Sign Up method empowers residents, staff and organisations with knowledge of the rights set out in the Convention, how to claim them and how to embed them in practice. Having residents take part and lead most of the process empowered them to use their voices to effect change in how care is delivered.

Legality

The Convention places the experiences of residents of care homes into the framework of human rights, highlighting that the matters discussed were human rights protected in law. For example, residents’ input such as “Staff don’t always knock on my bedroom door when entering” became Article 5 “Residents have the right to privacy and confidentiality”, based on rights found in the Human Rights Act 1998 and international human rights standards.

CASE STUDY SIX: HEALTHCARE IMPROVEMENT SCOTLAND

Introduction

Healthcare Improvement Scotland is the national organisation which drives improvements in the quality of healthcare people receive in Scotland. There are a number of distinct programmes within the organisation. Healthcare Improvement Scotland have been exploring the benefits of embedding human rights more explicitly in their work. To begin with, they decided to focus on two existing programmes of work. Healthcare Improvement Scotland is now considering how this approach can be used across the organisation to ensure human rights are at the heart of delivering their work.

The two programmes chosen were:

- ◆ **Our Voice** – a programme to build a stronger system for hearing the voice of service users and the public in health and social care services. Its purpose is to create a framework which will support people to give feedback about their experience of services. This feedback will be used by service providers to drive forward Scotland’s health and social care services.
- ◆ **Scottish Patient Safety Programme – Mental Health (SPSP-MH)** – this 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 implement interventions reliably, before spreading across their NHS board area.

These areas were chosen as the programmes had already identified that respecting the rights and interests of particular groups was especially important to their work.

The Scottish Human Rights Commission agreed to provide advice and support for this process. The Commission delivered a training session for relevant staff to explore human rights in the work of the programmes and to consider tools for embedding them in practice. After the session, the leads of both programmes were tasked with considering how they applied each of the “PANEL” principles in their work (see below). This allowed them to see where they were already using the principles and to highlight any gaps and weaknesses. SHRC gave feedback and suggestions on these assessments, acting as a ‘critical friend’. Both programmes identified additional steps they could build into their work.



What they say

“As an organisation, we are very committed to working with people, whether that’s people using services, carers, communities, frontline staff. So on that basis we felt we were probably doing pretty OK in terms of human rights but we didn’t actually have a way of testing that consistently across the work we were doing and looking really critically at it in terms of whether we could be doing more.”

SANDRA MCDUGALL, HEAD OF POLICY, SCOTTISH HEALTH COUNCIL
(A COMMITTEE OF HEALTHCARE IMPROVEMENT SCOTLAND)





“A human rights based approach puts the service user or the patient as well as the carer at the centre of everything we do. It refocuses the mind and keeps us away from being too bureaucratic and too number-crunching. It is very much about putting people first.”

STEVEN ROBERTSON, PROGRAMME MANAGER, SPSP-MH



Putting PANEL into practice

Participation

The Our Voice framework has been shaped by engagement with people and communities, and there will be ongoing engagement in its implementation.

The SPSP-MH connects with voluntary mental health organisations such as VoX, a mental health service user-led organisation, and carers' organisations in designing and evaluating its work. Service users are involved in developing changes to be tested in wards, for example, in designing a tool to assess the environment of patient safety on the ward.

Accountability

Both programmes already had developed accountability mechanisms, to ensure they delivered on all their goals. Through this process they considered how to ensure accountability for delivering human rights was specifically considered, such as building in steps to monitor this and report on progress through existing mechanisms.

Non-discrimination and Equality

The programmes had given consideration to how groups identified under equality legislation were impacted by their work. By considering the human rights angle, both programmes identified gaps in the stakeholder engagement activity that had already taken place, such as people experiencing homelessness or refugees. They also looked to identify those most marginalised in their sector.

Empowerment

Both programmes have a focus on empowering people who use services by increasing their voice and representation in shaping the work. Using a human rights based approach, they considered additional actions to empower people, such as building human rights awareness into capacity building activities with people and communities (Our Voice).

Legality

The programmes were keen to explore this approach as they had identified the importance of human rights to their work. The process led them to find ways of more explicitly recognising the connections between particular areas and human rights (e.g. restraint procedures and the right to private and family life) and to use tools to make decisions based in human rights. The SPSP-MH is testing the use of the FAIR tool (Facts, Analysis of Rights, Identification of Responsibilities and Review) in discussions with staff about how people's rights are impacted in particular mental health service scenarios.

Find out more

This guide has been produced as part of Scotland's National Action Plan for Human Rights (SNAP).

One of SNAP's main aims is to enhance respect, protection and fulfilment of human rights to achieve high quality health and social care. This includes work to embed human rights in the integration of health and social care, person-centred approaches and the National Care Standards. Other priorities include action to realise the right to independent living, securing more understanding and respect for human rights in mental health care and treatment and enabling the health and care workforce to put a human rights based approach into practice.

A Human Rights Action Group on Health and Social Care is coordinating action on these, and other priorities. The Action Group is jointly convened by the Health and Social Care Alliance and NHS Health Scotland.

You can find out more about SNAP at
www.snaprights.info

Short films showing each case study in action are available online at
www.healthandsocialcare-snap.com/case-studies

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