I would like to thank colleagues in the NHS organisations who have taken part in the Human Rights in Healthcare Programme 2011-2012 both for all their hard work and for developing an exciting range of new approaches to putting human rights at the heart of healthcare which other health and social care organisations can learn from.

I am especially grateful to Ellie Keen from the British Institute of Human Rights for her tremendous support for the programme and the NHS organisations involved. Ellie was stimulating and challenging and worked incredibly hard. She ran learning events about human rights; provided advice and support; made helpful comments on numerous drafts of documents; did a lot of the drafting of the Sunderland patient questionnaire and acted as ‘quality control’ making sure all the outputs of this phase of the Human Rights in Healthcare Programme are as good as they can be from a human rights point of view.

I also want to thank Alice Donald of the Human Rights and Social Justice Unit, London Metropolitan University who has worked alongside the NHS organisations involved and produced an excellent Guide to Evaluating Human Rights Based Interventions in Healthcare. We know a human rights based approach works. Using the Evaluation Guide enables us to prove it.

Finally, I must thank the Department of Health for funding the Human Rights in Healthcare Programme 2011-12.

Lindsey Dyer, Programme Lead
NHS organisations are public authorities and have positive obligations (Human Rights Act 2000) to respect, protect and promote human rights.

Since 2005, the Department of Health, the British Institute of Human Rights and a small number of NHS trusts have worked together to develop a framework and practical examples to assist NHS bodies to develop and apply a human rights based approach (HRBA) in their organisations.

The 2011-12 Human Rights in Healthcare Programme has been led by Mersey Care NHS Trust with funding from the Department of Health. The aims were to:

• Develop an online web resource – a one stop shop for information about a human rights based approach in healthcare (www.humanrightsinhealthcare.nhs.uk)
• Grow a network of people interested in human rights in healthcare and arrange some learning events
• Develop some good practice examples of how a human rights based approach can be applied in healthcare settings
• Develop an evaluation framework so that we can show a human rights based approach is useful – not only because we must respect, protect and promote human rights (this is non negotiable) but because paying attention to human rights makes a positive difference to the quality of care and the experience of patients and staff.

This report provides an overview of how four NHS organisations have been working in 2011-2012 to embed a human rights based approach into practice and make a real difference in peoples lives. The report also looks at the importance of evaluating human rights in healthcare projects and doing so in a way that adopts the same human rights principles as the projects themselves. It also summarises the important role played by HRHR in helping to build human rights into the delivery of health and social care. I hope it will encourage other organisations to look at ways in which they too can respect, protect and promote human rights in health and social care.

THE HUMAN RIGHTS IN HEALTHCARE PROGRAMME 2011-2012

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INTRODUCING HUMAN RIGHTS

There are some key things NHS organisations need to know about human rights:

• Human rights are about our basic needs as human beings
• Human rights belong to everyone, all of the time – not only certain groups or at certain times
• They cannot be ‘given’ to us – only claimed or fulfilled
• They cannot be taken away from us, only limited or restricted in some circumstances
• They are about how public authorities, such as NHS organisations, must treat everyone as human beings.

In essence human rights are a set of universal minimum standards that must be met. They are not only about the protection of particular individuals and groups in society but are a practical framework to protect the rights of everyone.

These rights are enshrined in International, European and Domestic Law and a key source is the Human Rights Act 2000 (see appendix).

WHY HUMAN RIGHTS ARE IMPORTANT IN THE NHS

Human rights values such as Fairness, Respect, Equality, Dignity and Autonomy (FREDA) underpin the public service ethos, the NHS Constitution and NHS professional codes of conduct, but things can still sometimes go wrong. For example, figures from the Office for National Statistics (2010) show that 1,316 deaths in hospitals were linked to, or directly caused by dehydration and malnutrition although hydration and nutrition are essential for sustaining life. If we take seriously the obligation on NHS organisations to respect, protect and promote human rights then we need to look through a human rights lens and see deaths in hospitals caused by dehydration and malnutrition as a human rights issue. Article 2 of The Human Rights Act 2000, The Right to Life. The bottom line is that human rights, like the right to life, are not a gift that NHS staff can give to patients. NHS organisations must respect the law and all the rights contained in the Human Rights Act (see appendix) in everything that they do.

This is not something to be frightened of. As you will see from the case studies, the framework of the Human Rights Act itself can be very useful for decision making at policy and day to day levels by staff. Looking at issues through a human rights lens can help NHS staff see things from a different perspective, improve attitudes and practices and provide a really useful framework for making difficult decisions.

By putting human rights at the heart of health services we can not only comply with the law but also improve the quality of health care. All those involved in the Human Rights in Healthcare Programme 2011-2012 have been taking seriously the obligation NHS organisations have to respect, protect and promote human rights and have come up with some really interesting and exciting ways of doing that. They provide important examples of how to bring about a new culture of respect for human rights in healthcare in the UK.
OVERVIEW OF THE ORGANISATION

Betsi Cadwaladr University Health Board (BCUHB) is the largest health organisation in Wales, providing the full range of primary, community, mental health and acute hospital services for a population of around 676,000 people across the six counties of North Wales (Angelsey, Gwynedd, Conwy, Denbighshire, Flintshire and Wrexham) as well as some parts of mid Wales, Cheshire and Shropshire. BCUHB employs around 16,772 staff, has a budget of around £1.2 billion and responsibility for the operation of three district general hospitals (Ysbyty Gwynedd in Bangor, Ysbyty Glan Clwyd in Bodelwyddan and Wrexham Maelor Hospital) as well as 22 other acute and community hospitals and a network of over 90 health centres, clinics, community health team bases and mental health units. BCUHB also coordinates the work of 121 GP practices and NHS services provided by North Wales dentists, opticians and pharmacies.

REASONS FOR INVOLVEMENT

Healthcare providers have a statutory requirement to monitor and improve standards as part of the Health Act (1999) and this drive to improve quality and consistency is embedded in the Betsi Cadwaladr University Health Board Strategic Direction (2009 – 2012) and BCUHB values (2011) of making it sound by putting patients at the heart of everything we do; making it happen by working together for patients; making it work by learning and being innovative in all that we do; making it safe by valuing and respecting each other; and making it better by communicating openly and honestly.

Nationally and internationally there have been a number of best practice frameworks, guidance and initiatives that set the standards for hospital catering and patient nutrition. There do not however, appear to be specific guidelines which make a direct link between hydration, nutrition and human rights, particularly in relation to the obligations of service providers which follow from the Human Rights Act (2000). Adopting a human rights approach to nutrition and hydration therefore was adopted as an innovative way of delivering excellence in nutrition and hydration by firmly placing the patient at the centre of care.

In the last few years a number of reviews have identified considerable failings in the NHS in particular relating to the care of older people (Patients Association, 2009, Ombudsman, 2012 and the Older People’s Commissioner for Wales, 2011). Consistent themes were not consistently providing dignified, high quality care, including not ensuring that patients have adequate nutrition and hydration. The Care Quality Commission review (2012) found that a number of hospitals failed to meet legal standards in providing patients with enough to eat and drink. These failings add to the high profile reports and public campaigns over the last 10 years which include the Essence of Care (Department of Health, 2001), Fundamentals of Care (Welsh Government, 2003), Nutrition Now (Royal College of Nursing, 2007) and Still Hungry to be Heard (Age Concern, 2010). Most recently the Patients Association, as an independent advocate for high quality healthcare, launched the CARE campaign, which is designed to improve fundamentals of care aspects that are most often not met including nutritional intake.

The need to deliver excellence and innovation was a driving force for this project and clearly linked human rights in healthcare with the evidence base for nutrition and hydration and the underpinning strategic direction for high quality, evidence based patient centred care.

PUTTING HUMAN RIGHTS AT THE HEART OF NUTRITION AND HYDRATION: A TOOLKIT FOR WARD SISTERS AND CHARGE NURSES
THE APPROACH WE TOOK

A project team was established in October 2011 and this included representatives from clinical staff, the equality and human rights team, catering, speech and language, dietetics, transforming care, education and a service user representative. Project meetings were scheduled monthly for the full 12 months and the project plan developed, including timelines for completion of the project. A transformational sub group was already in place and the remit of this group was changed to focus on the development of the toolkit.

Early meetings concentrated on where we are now and where do we need to be, with an initial training day held by the British Institute of Human Rights (BIHR) and Mersey Care NHS Trust which helped us as a group to focus on nutrition and hydration in the context of human rights. Service improvement methodology was used, which helped to narrow the focus and develop a driver diagram identifying the aim, primary and secondary drivers and interventions, resulting in a draft toolkit.

In March 2012 we held a full day stakeholder event, which was well attended with representatives from clinical staff, equality and diversity, catering, speech and language, dietetics, transforming care, education and service users. On arrival attendees were asked to complete a questionnaire regarding knowledge of human rights and the day was then split into initial presentations from Mersey Care, BIHR and BCUBH explaining the project and the aims. The afternoon session was focussed on group work, with the groups given the driver diagram and the draft tool kit; stakeholders identified six key areas for intervention which resulted in further defining the toolkit.

A further training event was held by BIHR for the Director of Nursing and Matrons, with the afternoon session specifically for the pilot wards and wider multidisciplinary teams. Six pilot wards had then been identified across the three main district general hospitals including care of the elderly, acute orthopaedic, acute surgical and acute medical wards. A senior nurse lead was identified for each site, working with the wards to test each element of the six key components and the associated interventions. Institute for Health Improvement service improvement methodology was used through the Plan-Do-Study-Act (PDSA) cycle or small test of change – by planning it, trying it, observing the results, and acting on what is learned. The senior nurse leads met weekly with their teams, conducting tests of change, analysing the results and then further shaping and defining the interventions. This service improvement methodology allowed staff to look at their own practice, barriers and enablers to delivering best practice and think outside the box in relation to potential solutions effectively giving them a voice in decision making and an ability to influence their practice, in a supportive environment.

THE TOOLKIT

The six wards have been enthusiastic, motivated and prepared to question and challenge their own practice as a result of the tests of change, all of which have helped shape and change the toolkit. The final toolkit therefore is a practical, user friendly document that has used a human rights based approach to care that has been developed by drawing upon the experiences of service users, staff and the organisation, and championed at board level by the Director of Nursing, Midwifery and Patient Services. It has a number of defining principles and six key components of Safety, Environment, Audit, Meal times, Choice and Empowerment with the patient firmly at the centre. These six key areas have a range of related interventions which have been identified by stakeholders to put human rights at the heart of hydration and nutrition.

KEY LEARNING POINTS

In summary the development and piloting of the nutrition and hydration toolkit has provided the Health Board with a number of opportunities:

- Improved knowledge and awareness about human rights for those involved including: the project team, stakeholders, and pilot wards but additionally matrons and other key colleagues.

- A multidisciplinary project team, including service users, speech and language, nursing, equality, dietetics, catering and six diverse ward teams to lead the way in shaping and developing this innovative project.

- Partnership working to closely align the human rights and fundamentals of dignified care agendas by driving forward high quality nutritional and hydration standards of care.

- Provided useful learning and a practical human rights based toolkit which other health organisations may wish to adopt.

FUTURE DEVELOPMENTS

It is envisaged that the toolkit will be a living document, with further refinement as a result of changes in policy, practice and national drivers. Future steps include the implementation of the toolkit across the Health Board; the terms of reference of the steering group are under review to focus on education, implementation and evaluation.

Evaluation of the impact of the toolkit on patient outcomes, staff knowledge of human rights, and overall improvement in nutritional and hydration care for the six pilot wards is underway and this will continue as the toolkit is embedded in everyday practice. A resource file for ward areas and easily accessible information via the nutrition intranet site is also in development, along with how the toolkit can be adapted for the independent sector and continued partnership working with universities and colleges to embed the knowledge and skills within our current and future workforce.
AIMS
To embed a human rights based approach into the emerging Health Watch to facilitate the development of Health Watch Board members in developing their competency in relation to human rights and to develop a guide to support the Blackburn with Darwen Shadow Health Watch Board.

BACKGROUND
The Care Trust Plus takes a human rights based approach to all decision making and as a systems leader in the borough we felt it was right for the Trust and the people we serve to be part of this project. The Trust serves a diverse registered population of approximately 140,000 people from diverse backgrounds. We have the third largest Muslim population outside of London and our population has a high percentage of under 16 year olds but also a very ageing population. We have some of the lowest life expectancy across the northwest and some high levels of deprivation too, all of which leads to us having a population who have many needs from a health and social care perspective and as a Trust we are proud of working alongside local people and empowering them to be involved in decision making.

As the role of the Trust changes in line with the proposed NHS changes there is scope for the Care Trust Plus to influence the emerging NHS structures including the proposed new Clinical Commissioning Group (CCG), Health and Wellbeing Board and Health Watch. This new and emerging environment created by the Health and Social Care Act 2012 has provided an opportunity for the Trust to embed human rights into these new structures as part of their development programmes.

We have taken a whole systems approach to taking a human rights based approach to commissioning for health and wellbeing and the role of Health Watch is a pivotal role in that it will act as an advocate for local people with a place on the Health and Wellbeing Board, and holding the CCG to account around its decision making processes for buying health care to meet the needs of local people.

It was agreed with the Health Watch project team which consisted of representatives for the Trust, borough council and the LINK that focusing on embedding a human rights based approach was an important part of developing the emerging Health Watch.

OUTPUTS
The outputs from the Trust taking part in this programme of work will be:
• Training for existing LINK members, those interested in applying to sit on the new Shadow Health Watch Board and the project group members
• A human rights based guide for Health Watch to support entering and viewing of health and social care provider premises.
OUTCOMES

This project has at times been difficult purely due to the changes taking place within the health and social care arena. Tying the project down to a manageable project with tangible outcomes was at times difficult to do within an arena of competing demands and changing leadership. However with all that, there were some definite clear outcomes for the project lead, the Trust and for the emerging Shadow Health Watch and these were as follows:

The Project Lead - the opportunity to work with both Lindsay and Ellie has been inspiring, enabling the lead to include a human rights based approach across a range of areas both within the Trust but inspiring other NHS and community groups to also take on a human rights based approach. It also enabled her to write the ‘What Does Good Look Like for Authorisation’ guide for CCGs. This guide was taken up by a range of emerging CCGs and primary care trust clusters to help guide their emerging CCGs in developing their strategies and governance around equality and human rights.

The Trust - in its role in supporting the development of the emerging CCG has been able to embed the human rights based approach into the new CCG governance arrangements, Equality and Human Rights Strategy, the Communication and Engagement Strategy and the Equality Analysis and Human Rights Assessment process.

The Shadow Health Watch - The emerging Health Watch Board members have had development workshops around human rights and a human rights based approach and have been instrumental in developing the guide.

LEARNING POINTS

Don’t try to be over ambitious as the level of knowledge about human rights, let alone human rights based approach, ranges from knowledgeable to ‘… dont see why I need to know’.

Think about the language you use when presenting your compelling business case – clinicians don’t talk in legislation, they talk in patient experiences and outcomes. I had a conversation with a clinician who was just not getting human rights until we discussed a cancer plan he was working on. I explained that if the plan set out a blanket ban on a cancer drug, but NICE guidance said that in some cases the drug was effective, the blanket ban would indeed engage those peoples Article 2, The Right to Life and possibly Article 8, The Right to Family Life, in that without the drug they might die rather than being cured or may have less life because they did not get the drug. It was at this point that he could see why it was so important to consider human rights and why a human rights based approach is so valuable.

Be tenacious because if we don’t champion this agenda then as NHS employees we are not valuing the people we work with and serve.

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BACKGROUND

City Hospitals Sunderland NHS Foundation Trust (CHSFT) is an acute trust providing a wide range of hospital services such as A&E, surgical and medical specialties, therapy services, maternity and paediatric care. The organisation has a key focus on ensuring the best possible care is delivered to patients at all times. In joining the Human Rights in Healthcare project CHSFT wanted to ensure we could find a way of measuring all experiences in our organisation based on a human rights approach. As part of City Hospitals Sunderland NHS Foundation Trust assurance purposes, we wanted to know that equality and human rights were being supported and delivered as part of standard patient care. At the same time the Equality Delivery System (EDS) was developed by the Department of Health (DoH) to ensure equality and to some degree evidence of compliance becomes embedded in access to and provision of all healthcare services for all groups. The Care Quality Commission (CQC) has agreed, as part of the review process they will look at how organisations are learning from the EDS and improving the grading.

WHAT WE DID

In order to achieve a baseline we wanted to design a survey to look at patients and staff views of human rights within CHSFT. Working as part of the Department of Health Human Rights in Healthcare programme gave us the opportunity to explore and develop the patient survey tool. We agreed following the development of the tool we would run a pilot study to understand how the survey was interpreted by the volunteer interviewers, how the survey was used and understood by patients, and the value of the questions in terms of information feedback. Finally we evaluated what, if any, changes needed to be made and pathways forward. The patient survey was drafted by the British Institute of Human Rights (BIHR) with input from CHSFT and the Royal College of Nursing. The pilot survey was then undertaken in two outpatient departments as well as inpatient services within City Hospitals Sunderland. The information was used to identify gaps within the service provision in relation to human rights for patients and to understand patients experiences and views.

PREPARING THE SURVEY

The final draft of the survey was human rights ‘proofed’ by BIHR who then led a training session with the volunteers from our local community, as they would be carrying out the survey. The volunteers are not employed by CHSFT allowing a non biased approach when collecting patient led data. The training consisted of understanding articles of the Human Rights Act, how human rights involve everyone, how human rights apply to healthcare, what to look for whilst carrying out a survey, improving cultural awareness for patients in healthcare and comparing and contrasting human rights within the UK and abroad.

UNDERTAKING THE SURVEY

We had originally expected to trial the service users survey and how it related to care of the elderly patients on the wards as well as two out patient departments (Endoscopy and Audiology). We quickly realised that with many patients in elderly care, many issues arose regarding consent and capability to be involved in the survey. However, by involving all patients throughout the hospital we knew the survey would be more robust and would allow many other issues to be raised from a wider group of service users.

Prior to commencing the survey we thought that a diversity questionnaire should be attached to the back of the survey as this would benefit the survey questions and allow us to identify any links with any possible potential human rights violations within any of the nine protected characteristic groups. To ensure that the volunteers were not asking any sensitive questions, the questionnaire was given to the service user to fill in for themselves and kept in a sealed envelope for data protection.

The volunteers were instructed to discuss any human rights concerns or matters of urgency with the lead member of staff and then follow up with Austin O’Malley, Equality and Diversity Co-ordinator or Stephanie Smith, Project Choice Regional Programme Manager. The volunteers were also given a questionnaire, which asked questions around how they felt regarding carrying out the survey, identifying positives/negatives in terms of patient responses and their feelings undertaking the survey as well as topics for possible further development of the survey.

To do this we brought the volunteers together after the survey had been completed, discussed the results and how we could develop and improve the tool and whether it was possible to use the tool without human rights training.

PATHWAYS FORWARD

Taking this survey forward, there are some aspects which have been changed reflecting the feedback from the volunteers. One area which had been developed was the addition of the diversity questionnaire on the back of the survey form. This allowed a more in-depth result to be carried out from the additional information given from the service user. If any red results were found in the rag rating format of the questions, this would give a better understanding as to why the red was issued and show if we have more reds or ambers for particular protected characteristics groups.

Another addition to the human rights survey tool was the introduction of an evaluation tool to show how many small issues can develop into potential human rights violations. It also identifies the steps needed to take action at certain areas within the survey. We are also looking to develop an overall evaluation tool which can be used in a ward/department to not only identify issues but also actions to be taken following certain triggers. It would be hoped after developing the evaluation tool the survey can be used to prevent escalation of concerns.

Finally, we have set up the City Hospitals Sunderland NHS Foundation Trust Human Rights Steering Group. This will allow further development of the survey tool. It has already been identified by the volunteers that we need a carers human rights survey and with the completed staff survey this would allow a triangulated approach and ensure a more robust assessment in areas where care is provided.

We would like to thank Wilfred Curry, Linda Davidson, Dave Green and Thomas William Holson from the City Hospitals Sunderland Human Rights Group for their amazing help and contribution in developing and carrying out this survey tool.

FOR FURTHER INFORMATION

CONTACT

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Liverpool Clinical Business Unit (CBU) is part of Mersey Care NHS Trust which is based in Liverpool and provides specialist mental health services.

**REASONS FOR INVOLVEMENT**

During the process of developing a person centred model of care for people with dementia for the inpatient wards, the proposed model was presented at a service user forum. It was suggested that the model of care would fit within a human rights based approach which would provide a more robust framework.

Mersey Care has adopted a human rights based approach so it fitted with the culture of care within the organisation. There is relatively little in the literature about a human rights based approach in the area of dementia. This is despite the fact that people with dementia are a group of people who are vulnerable in terms of not having their human rights considered and at times violated. This is as a result of a culture of care which has disregarded and devalued people with dementia based on the fact that their cognition is compromised and they have therefore often been treated in a way that has undermined their human rights.

**THE APPROACH WE TOOK**

Initially a project team was set up with representatives of different disciplines, ward staff, people with dementia and a project lead and manager were appointed. It was important to gather motivated staff with a keen interest in the area and who were prepared to work hard on the project. The initial meetings were about developing ideas for the project and then working on a project plan. The project plan was then developed. As we were being supported by some time from the British Institute of Human Rights (BIHR) it was necessary to highlight what input was necessary from the outset.

**1 ASSESSMENT TOOL**

The group decided to develop an assessment tool that encompassed the principles of person centred dementia and framed it within a human rights based approach. The focus of the assessment would be on maximising the person’s quality of life whilst they were on the ward and ensuring that their human rights were supported and upheld. The wider team received a days training from the BIHR.

A literature review was carried out to establish whether this work had been done before and to inform the construction of domains for the assessment. The domains for the assessment were developed following focus groups with the project team and wider team and utilising the information from the literature review. This has been a reiterative process.

The assessment document is held by the person and contains a care plan which was developed with them. The document is called ‘Getting it right’.

The assessment tool consists of a person held record and a staff manual. The staff manual contains standard questions which should be asked of all service users. To ensure the assessment is completed well and provides maximum quality of life for the person whilst they are on the ward, it is staged and colour coded to prevent the person feeling overwhelmed. The wellbeing of the person should always be the guide for staff when completing the assessment.
2 LEARNING RESOURCE

The second part of the project was to develop a learning resource for staff. The learning resource contains information about the Human Rights Act, human rights based approach and dementia, a scenario to enable staff training, and training and instructions and modelling on completion of the assessment.

Staff will be trained using drama to enact a scenario which has occurred on the ward to enable staff to view it before the training and then review it once they are aware of the principles of a human rights based approach. The human rights based approach will enable a different approach to be considered when making decisions.

3 DVD

Following the training event a DVD is being commissioned to professionally produce a scenario which can be used for learning in other services. It involves working with script writers and actors to present a scenario similar to that described above which contains the perspectives of the person, staff, carers and BHR and which encourages discussion amongst staff teams about how a human rights based approach can assist them in decision making and working with people with dementia.

EVALUATION

The project is being evaluated in the following ways:

- Care plan audit. Using service developed standards (using Kittiwode model of enriched dementia) an audit of care plans was carried out before the training and the adoption of the ‘Getting it right’ assessment. It will be repeated after the implementation of the tool to establish whether there is any difference.
- Semi-structured interviews carried out with staff pre and post training and implementation. The interviews will use vignettes which highlight human rights issues and staff will be asked about decision making and what influences their decision making with regard to how they intervene, pre and post training and implementation. This is to establish whether using a human rights based approach, which they will learn about in the training, provides a more robust framework to help make decisions with regard to intervening.
- Knowledge questionnaires with regard to human rights – assessed pre and post training.

OUTPUTS

1. ‘Getting it right’ person held document - assessment summary and care plan for the person, developed with the person.
2. ‘Getting it right’ staff manual - this is the manual for staff to carry out the assessment. It contains standard questions and actions for the staff member to carry out.
3. ‘Getting it right’ resource pack - a pack which accompanies the staff manual containing further prompts to enable the person with dementia to understand what is being asked - pictures, emotion flash cards, information leaflets that are easily understood and written for people with dementia.
4. ‘Getting it right’ learning resource - PowerPoint presentations, session plans, discussion questions and quizzes for the training day that staff need to complete before delivering the assessment.
5. ‘Getting it right’ DVD - accompanying DVD to enable staff to view a scenario involving a person with dementia and many of the commonly occurring issues within a residential setting, scenes to help understand the perspectives of all participants and the principles of a human rights based approach. It also contains a section on completion of the ‘Getting it right’ assessment.

KEY LEARNING POINTS

Involves service users from the outset of the project.
A highly motivated team is essential as is a team who are willing to work hard.
Keep it simple, it is admirable to have high aspirations but difficult to achieve if the project is too ambitious.
Keep the evaluation methods simple.
Keep in touch with all partners throughout the project.
Building a project plan and having key milestones to reach keep the focus and momentum going.

FOR FURTHER INFORMATION CONTACT

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WHO WE ARE

Rebuild Clinical Business Unit (CBU) is part of Mersey Care NHS Trust which is based in Liverpool and provides specialist mental health services. Rebuild provides specialist health services for people with learning disabilities, acquired brain injuries and severe, enduring mental health issues.

REASONS FOR INVOLVEMENT

Mersey Cares involvement in the Human Rights in Healthcare Programme has acted as a catalyst, galvanising staff and service users to tackle the inequalities, injustices and indignities within mental healthcare and associated services. The current project aimed to address the lack of engaging human rights materials available to or produced by people with learning disabilities.

THE TOOLS WE HAVE DEVELOPED

The people with learning disabilities that we work with have learned about the FREDA principles (Fairness, Respect, Equality, Dignity and Autonomy) which underpin a human rights based approach. FREDA has become much more than a simple acronym. She has become a character in herself, a person who treats others with Fairness, Respect, Equality, Dignity and Autonomy; someone who embodies human rights values and is used by people with learning disabilities as a touchstone to judge whether what is happening in their lives is supporting their human rights.

So we worked with them to co-produce a serious human rights board game named ‘FREDA Challenge’ and a DVD. These will be made widely available with the aim of increasing knowledge of human rights and of the FREDA values with people with learning disabilities, their carers and with healthcare professionals in both community and inpatient settings.

Two papers have been submitted to academic journals (one accepted so far) describing the work.

THE APPROACH WE TOOK

We have continued to take a relationally informed co-production approach. This combines the passion of the radical, activist tradition with the awareness that rights are codes for understanding social relationships operationalised through the developing models of the service user movement and evaluated using the rigour of scientific enquiry.

In practice, this meant:

• Jointly developing resources with groups of service users, featuring FREDA as a character embodying human rights values and using FREDA as the main vehicle for learning.

• Using dilemma-based learning – using vignettes and personal stories to help understand the principles of human rights.

FREDA CHALLENGE – A HUMAN RIGHTS BOARD GAME

The human rights board game project involved multi-disciplinary professionals and service users from the Trust’s intellectual disability services and brain injury rehabilitation. Initially, the group played a wide variety of board games together, considering factors such as engagement, accessibility for people with intellectual disabilities, and how best to facilitate learning. The group then considered human rights, and which key aspects they would like other people to learn about. The first prototype of the FREDA Challenge board game comprised of a board, three sets of cards, and a dice. Players make their way around the board, picking up cards as they go (which either give facts about human rights or give chance elements such as an extra turn). The aim of the game is to collect a full set of FREDA cards. Each card describes a dilemma based scenario whereby a human right has been violated, and asks group members to consider what FREDA might say. Once a player has collected all five FREDA principles, they can progress to the centre of the board; the first person to do so wins the game.

The prototype board game was evaluated with eighteen people with learning disabilities and thirteen carers/professionals. Human rights knowledge and attitudes were measured before and after participants played the game. Overall satisfaction with the game was also measured. Analysis revealed high levels of knowledge about and attitudes towards human rights in the carers/professional group. There were statistically significant changes in attitudes and knowledge of the group of people with learning disabilities after playing the game but not in the carers/professionals group. Overall satisfaction was positive, improvements to the game were recommended and changes made.
Co-production as a method of inclusion may help redistribute the power for individuals with intellectual disabilities open up and speak up for themselves… it doesn’t matter if we’ve got disabilities or not we have got the choice to do what of human rights.

DVD. Service users supported one another to create a safe environment where they felt able to share their own personal experiences. The DVD uses the group members own personal stories and experiences to highlight the FREDA principles. Knowledge and being part of the group appeared to engender a sense of belonging and empowerment, ‘It got people to and help others think about and understand human rights for people with intellectual disabilities. To our knowledge it is the first truly co-produced DVD of its kind where service users have been actively involved right from initial design and planning through to final editing and dissemination. All the service users have been heavily involved in the filming by being interviewed and taking part in the dramatisations of their stories.

KEY LEARNING POINTS
1. Learning through personifying FREDA
   Service users internalised Freda, making her a person and thinking about what she would say when people were faced with breaches of their human rights or difficult situations: ‘Freda means to me that you’re learning to stand up for yourself but also learning about your human rights… you start to learn to grow within yourself’. (Service user FREDA Fighters, 2012).

2. Dilemma based learning
   People seem to find using vignettes and personal stories to be a helpful way to learn and to help understand the principles of human rights.

3. Learning and solidarity through being part of a group
   There was a powerful sense of having a shared experience with other service users, and of feeling less isolated, ‘I thought I was the only one but finding out there’s others has helped me.’

   Knowledge and being part of the group appeared to engender a sense of belonging and empowerment, ‘It got people to open up and speak up for themselves…it doesn’t matter if we’ve got disabilities or not we have got the choice to do what we want to do in life.’

   Co-production as a method of inclusion may help redistribute the power for individuals with intellectual disabilities giving them more control and enabling them to become active agents of change.

Future developments
These are likely to involve:
- Co-produced services and training within Rebuild services.
- Evaluation of a revised prototype of the board game. Develop a business case, partnership working and funding to enable large scale production of the FREDA Challenge, and dissemination of the DVD.
- Research developing assessment of implicit (versus the explicit attitudes measured here) attitudes to human rights.

EVALUATING HUMAN RIGHTS BASED INTERVENTIONS IN HEALTHCARE
My name is Alice Donald and I am a Senior Research Fellow in the Human Rights and Social Justice Research Centre at London Metropolitan University. My research interests include the impact and implementation of human rights in the UK. As this report shows, the practical application of human rights in healthcare is gathering pace. Much has been learnt and in some health and social care organisations, human rights have started to become embedded in everyday practice and culture. What impact have human rights based approaches had on people using services, staff and the design and delivery of services? To find out, it is necessary to evaluate human rights based projects – and moreover, to do so in a way which adopts the same human rights principles as the projects themselves and is sensitive to the types of change that human rights based interventions seek to bring about.

As part of the Human Rights in Healthcare Programme 2011-12, I was commissioned to write a guide to evaluation. The guide is informed by previous evaluations of human rights projects in health and social care organisations and also by numerous stimulating and inspiring discussions with colleagues in NHS organisations taking part in the current phase of the programme.

The guide starts from the idea that human rights are both an end and a means – a set of legal standards, and a set of principles (and associated practical approaches) that underpin how those standards are achieved.

These principles are a helpful framework for implementing a human rights-based project, and also for evaluating it. They are encapsulated in the acronym PANEL:
- Participation in own decision-making
- Accountability of duty bearers to rights-holders
- Non-discrimination and prioritisation of vulnerable groups
- Empowerment of rights-holders
- Legality: the express application of a human rights framework.

What particular sorts of change do human rights based projects seek to bring about – and ever what timescale? What does it mean to change the culture of an organisation using human rights? How can evidence best be gathered to determine whether a project has achieved its goals? What ethical considerations need to be addressed? What are the common pitfalls facing evaluators? The guide will help to equip health and social care professionals, working in partnership with people using services and carers, to answer these questions.

The guide contains nine case studies and is accompanied by a document containing examples of road-tested evaluation tools that others can adopt – or adapt.

What are the most important lessons from previous experience of evaluation? Here are my suggestions:
- Identifying clear and specific aim and objectives is vital. If you are not clear at the outset about what you are trying to achieve, then it will be difficult to identify what success looks like – let alone identify or measure it. The guide explores how to design a process of change based on human rights, focusing both on what to change and who participates in and/or benefits from that change.
- The participation of service users and carers in decisions that affect them is an integral part of many human rights based projects. It follows that service users and carers should also participate in the evaluation of such projects.
- Such participation can have a transformational effect. Consider the difference between identifying outcomes that make sense to the life of a person using a service (who might ask, What will change for the better in my life?) and identifying outcomes that make sense to the professional (who might ask, What targets or indicators am I obliged to report on?)
- The findings of your evaluation will be more reliable if you use a mixture of methods. These may include both quantitative methods (to find out how many people thought or did something) and qualitative methods (to find out why people think or behave in a certain way or have certain preferences).
- Keep your evaluation realistic and proportionate to the scale of your project.

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The British Institute of Human Rights (BIHR) is an independent human rights charity. Founded over 40 years ago, we provide practical support and technical assistance to public and voluntary sector organisations so that they can ensure that the human rights of those they work to support are protected. We believe that the protection of human rights is not a task for the human rights community alone: it is only to be achieved if individuals and public bodies – rights-holders and duty-bearers - are aware of human rights and come to recognise their value and necessity. For rights-holders, the support we provide aims to raise such awareness and to empower groups and individuals who are most in need of protection to access their own rights more effectively. For service providers – those who bear obligations under human rights legislation – we aim to assist in embedding human rights into policy and practice, in a way which both supports their own work and ensures a better outcome for their clients.

WHO WE ARE

The British Institute of Human Rights (BIHR) is an independent human rights charity. Founded over 40 years ago, we provide practical support and technical assistance to public and voluntary sector organisations so that they can ensure that the human rights of those they work to support are protected. We believe that the protection of human rights is not a task for the human rights community alone: it is only to be achieved if individuals and public bodies – rights-holders and duty-bearers - are aware of human rights and come to recognise their value and necessity. For rights-holders, the support we provide aims to raise such awareness and to empower groups and individuals who are most in need of protection to access their own rights more effectively. For service providers – those who bear obligations under human rights legislation – we aim to assist in embedding human rights into policy and practice, in a way which both supports their own work and ensures a better outcome for their clients.

WHY WE BECAME INVOLVED?

Over the last year 10 years, BIHR has worked to support a variety of actors and initiatives to build human rights in the delivery of health and social care. In 2007, we developed the National Human Rights Framework for Health and Human Rights with support from the Department of Health, and we have also pioneered practical work on the ground with a number of primary care trusts, including Mersey Care. This project provided a further opportunity to work closely with a number of health providers and to explore the possibility for integrating human rights into health and social care. We had already seen the significant appetite throughout the public sector for embracing and exploring human rights based approaches to healthcare. Those who work in this sector – at all levels – have appreciated the clear legal framework which human rights provide, the common values they embody, and the assistance they can provide in assessing conflicts of needs or rights at an everyday level. It has been our experience that an understanding of human rights has provided clarity and reassurance, perhaps particularly for those working at the front line of health and social care. A common response has been that the human rights framework exemplifies the very reasons which led most to enter the service.

In recent years, there have been an increasing number of high profile reports concerning poor standards of care. Although such cases are perhaps the exception, we believe that human rights can assist providers of healthcare to develop more consistent approaches which are legally compliant, are easily understood by those responsible for delivery and which ensure better standards of care for all without exception. This project provided an exciting opportunity to continue the process of supporting such approaches.

HOW WE BECAME INVOLVED?

For most of the four trusts working under this project, we began by providing a basic level of training which addressed the human rights legal framework, key values, and a general understanding of a rights based approach as this relates to health and social care. Our support following this initial training was perhaps most necessary in helping to refine the tools created by the trusts – in particular, in checking the human rights content. This required a process of constant discussion and clarification from both sides: their superior knowledge of the particular area they had selected to work on, potential issues arising and normal ways of working meant that the human rights messages or the structure of the tools often had to be adjusted in order to suit the context or issue being addressed. In general, these discussions were extremely constructive and benefited from this two-way process.
KEY LEARNING POINTS

Human rights are not quick and easy, and the task of embedding human rights in structures as large and complex as a health trust is particularly challenging. It requires, firstly, a relatively good understanding of human rights legislation – in itself no small task. Secondly, it requires recognition on the part of service providers that the power or control they exercise over those in their care needs always to be justified, always respectful of every patient’s need for dignity and some autonomy. With certain individuals or groups, this recognition can sometimes call for extra effort and a small change in perspective. Thirdly, embedding human rights requires a genuine commitment – ideally from the top – to embed these ideas in policy and practice, to be honest about identifying weak points in the system and, where necessary, to make changes. Perhaps the most significant learning point has been that each of these stages requires significant time to become embedded, second nature. A human rights approach – just like an equality-compliant approach – needs commitment over the long term and consistent and constant efforts to educate and inform staff members.

The commitment, energy and expertise of those individuals who led the projects in each trust were both impressive and undoubtedly an important element in the success of developing the final tools. The project demonstrated their sincere belief that human rights could make a difference to their work, and a willingness to be innovative and to learn during the process. They also recognised the importance of involving other individuals – from service users, to volunteers, front line staff and senior management. The engagement of people at a number of different levels made a strong contribution to the quality of the tools and to the potential sustainability of the results.

In those trusts which were starting out and possessed little prior knowledge of human rights, we believe that more development time would have been very valuable in ensuring that key points were fully understood, and in helping to design and deliver first drafts of the tools which were closer to a final end product. Ideally, at least in such trusts, we felt it would have been valuable for the initial discussions on development, approach and the structure of the tools to have been undertaken with a more significant human rights input.

A further point which emerged relates to the difficult but highly important relationship between the values of human rights and their legal standing. The values which underpin human rights provide a powerful pedagogical tool to help people understand the purpose of human rights and the role they play in determining the kind of society we wish to create. The values, however, are the start and not the end of the journey. The real power of human rights in a healthcare setting is what they say about the authority or power which anyone working in a public service wields. There is a pressing need to ensure that the legal status of human rights is always reinforced alongside the values. Understanding the legal framework not only helps trusts to ensure legal compliance, it also assists in clarifying the values themselves, which otherwise may be liable to be interpreted in relatively subjective ways. Concepts such as fairness, dignity, respect have common language meanings which do not always overlap exactly with their accepted interpretation in a human rights context.

A final learning point relates to the commitment to this work from leaders in the pilot trusts. Some of the pilots had secured such support and it was evident that work on the tools progressed a great deal more rapidly as a result. There was also a degree of confidence that the work was likely to continue after the project end. In other trusts, a change in personnel or lack of genuine commitment perhaps left it in some doubt that the approach would be thorough-going – although it is recognised that these things take time, and it is certainly the case that a first initiative is an important step in moving towards a more comprehensive approach.

Finally, the appetite for change which we witnessed in this project reinforces our experience in other work across the public sector, where key individuals and units are recognising the value of human rights in embedding culture change, in leading to better conditions and better outcomes for service users and in providing a way to negotiate the many difficult decisions and conflicts which arise at an everyday level. We continue to admire and be encouraged by the energy and willingness of those working in the health and social care sector to be open to new initiatives - despite challenging working conditions and restrictions on resources. We are delighted to have been involved in this work.
APPENDIX: THE HUMAN RIGHTS ACT, 2000

The rights contained in the Human Rights Act are:

Article 2: Right to life
Article 3: Right not to be tortured or treated in an inhuman or degrading way
Article 4: Right to be free from slavery or forced labour
Article 5: Right to liberty
Article 6: Right to a fair trial
Article 7: Right not to be punished for something which wasn’t against the law
Article 8: Right to respect for private and family life, home and correspondence
Article 9: Right to freedom of thought, conscience and religion
Article 10: Right to freedom of expression
Article 11: Right to freedom of assembly and association
Article 12: Right to marry and found a family
Article 13: Right not to be discriminated against in relation to any of the rights contained in the European Convention
Article 1, Protocol 1: Right to peaceful enjoyment of possessions
Article 2, Protocol 1: Right to education
Article 3, Protocol 1: Right to free elections
Article 1, Protocol 13: Abolition of the death penalty.

It is important to remember that not all these rights are the same. There are three main types of rights – absolute, limited and qualified rights. The difference between them is explained in the glossary.

GLOSSARY

A Human Rights Based Approach (HRBA)
A human rights based approach is one where the realisation of human rights principles are a central aim in policy and planning, where staff and patients are empowered and involved in achieving these, where accountability is clear and the most vulnerable are prioritised. It is the process by which human rights principles are put into practice.

European Convention on Human Rights
The European Convention on Human Rights is a regional human rights treaty made by the member states of the Council of Europe after the Second World War. The Convention established a European Court of Human Rights, based in Strasbourg, France. The UK signed up to the Convention in 1951.

Human Rights Act
The Human Rights Act became effective in the UK in October 2000. It brought most of the rights contained in the European Convention on Human Rights into UK law. The Act places a duty on all public authorities to act in accordance with the rights protected by the Convention.

Public authority
The term ‘public authority’ is not fully defined in the Human Rights Act but it includes any person or organisation ‘whose functions are of a public nature’. NHS trusts are included. The term covers private organisations such as companies or charities but only when they are carrying out a public function.

Absolute rights
These rights can never be interfered with, not even in times of war or national emergency. Lack of resources is never an excuse for interfering with an absolute right. An example is Article 3, The Prohibition of Torture, Inhuman and Degrading Treatment.

Limited rights
These rights are not absolute. They may be limited in certain strictly defined circumstances. An example is Article 5, The Right to Liberty and Security. This right may be limited in circumstances including where someone has committed a crime or where someone is suffering from serious mental health problems.

Qualified rights
These rights are not absolute. They may be interfered with as long as the interference is (1) lawful, (2) for a legitimate purpose, (3) necessary and (4) proportionate (see proportionality below). An example is Article 8, The Right to Respect for Private and Family Life, Home and Correspondence.

Proportionality
A proportionate response to a problem is one that is appropriate and not excessive in the circumstances. The expression commonly used to capture this meaning is you should not use a sledgehammer to crack a nut.

Positive obligations
These obligations require authorities to take proactive steps to protect human rights. Positive obligations are often contrasted with negative obligations which require authorities to refrain from action that may violate human rights.
PUBLICATIONS


Dignified Care. Older Peoples Commissioner for Wales, 2012.


Older People and Human Rights, Age UK, 2009.


Whose Rights Are They Anyway, Carers and the Human Rights Act, Carers UK.

USEFUL WEBSITES

A Dignified Revolution
www.dignifiedrevolution.org.uk

British Institute of Human Rights
www.bihr.org.uk

Care Quality Commission
www.cqc.org.uk

Department of Health
www.dh.gov.uk

Equality and Human Rights Commission
www.equalityhumanrights.com

European Court of Human Rights Home Page
www.echr.coe.int

European Union Agency for Fundamental Rights
www.fra.europa.eu

Healthcare Inspectorate Scotland
www.healthcareimprovementscotland.org

Healthcare Inspectorate Wales
www.hiw.org.uk

Human Rights in Healthcare
www.humanrightsinhealthcare.nhs.uk

Joint Committee on Human Rights
(Houses of Parliament)
www.parliament.uk/jchr

Justice
www.justice.org.uk

Liberty
www.liberty-human-rights.org.uk

Mencap
www.mencap.org.uk

MIND
www.mind.org.uk

NHS Centre for Equality and Human Rights (Wales)
www.wales.nhs.uk/equality

Office of the UN High Commissioner for Human Rights
www.ohchr.org

Older Peoples Commissioner for Wales
www.olderpeopleswales.com

Scottish Human Rights Commission
www.scottishhumanrights.com