



Centre for Research in Education Inclusion and Diversity



CREID BRIEFING 20

KNOWLEDGE EXCHANGE ON PUBLIC POLICY IN SCOTLAND

PROMOTING BEST PRACTICE IN EQUALITY AND HUMAN RIGHTS IN SCOTLAND

A KNOWLEDGE EXCHANGE PROGRAMME SUPPORTED BY THE SCOTTISH FUNDING COUNCIL

WHAT DOES THE HUMAN RIGHTS AGENDA HAVE TO SAY ABOUT CARE AND DIGNITY?

Nicholas Watson and Joanna Ferrie
University of Glasgow

Sheila Riddell, Sheila Edward and Elisabet Weedon
University of Edinburgh

May 2009



University of Glasgow | Strathclyde Centre for
Disability Research

Introduction

This briefing paper reports on a “think-tank” event entitled ‘*What does the Human Rights Agenda have to say about Care and Dignity?*’ held at the Park Inn Hotel in Glasgow on 29 April 2009. This day was the fourth of five events in the knowledge exchange programme, *Promoting Best Practice in Equality and Human Rights in Scotland*, led by Professor Nick Watson, University of Glasgow and Professor Sheila Riddell, University of Edinburgh, with the support of the Scottish Funding Council.

‘What does the Human Rights Agenda have to say about Care and Dignity?’ aimed to create a space where people and professionals working to promote the human rights of people in receipt of care and health services could share ideas. The event brought together four papers from professionals working in this area: Alan Miller, Chair of Scottish Commission for Human Rights (SCHR); Maire McCormack, Head of Research at the Office for Scotland’s Commissioner for Children and Young People (SCCYP); Billy Watson and Charlie McMillan, from the Scottish Association for Mental Health (SAMH), and Gillian Dalley of the Relatives and Residents Association. The invited audience of 35 included voluntary and statutory sector professionals, national and local government officials, academic researchers and research students working in this area.

The specific aims of the event were:

- To share knowledge on the topic of care and dignity: to explore how a human rights discourse could improve the quality of services and the experience of receiving services; and to involve a range of bodies including Scottish Government, local authorities, academics and third sector organisations
- To reflect on current policy and to determine what information is required to advance reform to further promote rights
- To reflect on the knowledge exchange process and draw lessons for future events
- To produce a briefing with a ‘state of the art’ assessment of the current picture and key issues affecting Scotland.

This briefing paper is in four sections. The first summarises messages from each of the four presentations; the second explores themes generated by the small-group workshops which offered a different kind of knowledge exchange opportunity for all the speakers and delegates. The third covers issues and questions from the closing plenary, led by discussant Joanna Ferrie of the Strathclyde Centre for Disability Research; and the paper ends with reflections which draw both on the events of the day and on participants’ evaluations of it.

Presentations

Professor Alan Miller, Chair of the Scottish Human Rights Commission, confirmed that the promotion of human dignity in care had emerged as a key theme from the Commission’s recently concluded nationwide consultation on its draft strategic plan.

He based his comments upon the Universal Declaration of Human Rights (UDHR) which he introduced as the foundation of all modern human rights law of which equality was an inherent part. The UDHR provided such rights as the right to the highest attainable standard of physical and mental health, to an adequate standard of living, to autonomy, freedom of expression and the prohibition of inhuman and degrading treatment. All of these rights were to be exercised without discrimination, not only including but going beyond the specific equality “strands” incorporated in the Equality Bill. The point was emphasised that such rights were the means to protect and promote the inherent human dignity which is the birthright of each of us.

Alan then explained how the Human Rights Act 1998 gave effect to key rights under the European Convention on Human Rights. Such rights helped to provide us all with practical definitions, standards and guarantees of human dignity. Article 3 prohibits inhuman and degrading treatment and so protects individuals from abuses to their human dignity. Article 8 essentially provides the right to affirm human dignity in the sense of autonomy and personality. Both rights were inadequately understood in Scotland and their potential benefit as yet unrealised.

Alan proceeded to outline the essential features of a human rights-based approach as providing both the values and legal framework within which human dignity in care can most effectively be realised. This approach empowers those entitled to receive care, holds accountable those authorities with the duties to provide such standards of care as well as provides guidance as to how such authorities, and the practitioners involved, can best meet their responsibilities. Alan drew upon his experience of helping The State Hospital to operationalise a human rights-based approach. This had essentially been to develop an agreed common framework of rights and shared responsibilities of the patients, staff and management which had led to a demonstrable development of a human rights culture and had also enabled The State Hospital to more effectively than others deliver and integrate its equality duties within such an approach. The Commission was carrying out an independent evaluation of this experience so as to share the positive outcomes and benefits with the broader care sector.

Finally Alan clarified the relationship between human rights and equality. He explained that the UK had still to develop a modern and coherent human rights framework as had been repeatedly pointed out by the United Nations. The UK gave a disproportionate priority to civil and political rights and neglected economic, social and cultural rights – including the right to health. Within this distorted approach it also had given a disproportionate emphasis to and created confusion regarding equality. This created the false picture that human rights were somehow too complicated or adversarial to be of practical use and that certain specific and limited equality “strands” should be all that we concerned ourselves with. In fact equality was not separate or semi-detached from human rights but was in with the bricks of human rights. The equality duties under the Equality Bill could best be delivered by taking a human rights-based approach and this approach would be welcomed by practitioners who were tired of the process driven and box –ticking approach adopted to date. A culture shift was what was needed by all concerned and this was what the Commission had been established by the Scottish Parliament to help find the ways and means of achieving.

Maire McCormack, Head of Policy at SCCYP, focused on children and young people and specifically explored issues around assisting disabled children and young people. This presentation was based on the document ‘*Handle with Care*’ published by the SCCYP in 2008 (Paton, 2008).

She reflected on the role of the SCCYP, created following the Commissioner for Children and Young People (Scotland) Act of 2003 to promote and safeguard the rights of people up to the age of 18 years (and up to the age of 21 for looked after young people). The strategic outlook of the SCCYP necessarily embraces a rights-based philosophy to review law and policy, to promote awareness about rights (to children and young people and to service providers) and to promote best practice by service providers.

Indeed, the SCCYP looks closely at the United Nations' Convention on the Rights of the Child (UNCRC, 1989). The UNCRC covers the cultural, social, economic and political rights of all children and young people and is guided in interpretation by four founding principles: non-discrimination; the best interest of the child; the maximum survival and development of the child; and the consideration of children's views and opinions on all matters that affect them. The SCCYP has endeavoured to ensure that the interests of each child and young person are central to all decisions made regarding them, sometimes encountering a tension within service provision between rights and dignity, and health and safety. Legislation on health and safety in the workplace has often been misinterpreted resulting in over-zealous attention to safety issues to the exclusion of a consideration of the interests (best or otherwise) of the children and young people involved.

Maire also reported that children and young people can have an uncomfortable relationship with the issue of rights, caused by lack of clarity in the law and apparently contradictory guidelines. Further, there seems to be a lack of common sense in the ways that the law is interpreted. As a consequence children and young people may feel unable to challenge service provision or to promote their own rights, because they perceive this as reducing the rights of the people who provide care or health services.

A short DVD was shown, emphasising the impact service provision can have on reducing autonomy and independence. In the film disabled young people reflected on their experiences of being moved using harnesses, or not moved in a timely and responsive fashion. While they recognised the need to ensure health and safety safeguards were in place, they felt that they unnecessarily took precedence over their rights to dignity and respect. Several felt dehumanised by the experience of being handled, one described feeling like 'cargo'. The film and Maire's presentation brought into relief the essential need to see children, young people and adults as human beings first and service users second.

The contribution from SAMH involved **Billy Watson**, Chief Executive, and **Charlie McMillan**, Director of Research, Influence and Change. SAMH has a rights-based approach and is committed to promoting rights in all their strategies and functions. For example their anti-bullying campaign is hugely influenced by Article 26 of the Universal Declaration of Human Rights, as it fights for the right to education.

Billy began by reflecting on how mental health problems frequently co-exist with other forms of inequality. In Scotland the poorest 20% of the population are twice as likely to develop mental health problems; there is currently a 79% unemployment rate for people with serious mental health problems; and people with mental health problems are three times as likely to be in debt. Of critical relevance to this discussion about human rights is the fact that people with mental health problems can have their liberty withheld without being suspected or convicted of a criminal act – the only area of health where this is possible.

Charlie reflected on the legislative framework supporting human rights in the UK and Europe. Within the field of mental health, it seems that professional testimonies continue to gain greater credence, making it particularly difficult for a person with mental health problems to use legislation to appeal against an aspect of their treatment or experience. Despite some problems in applying legislation in practice, Article 12 of the UN's *International Covenant on Economic, Social and Cultural Rights* argues for the right to the highest attainable level of physical and mental health. Freedom from degrading treatment, the right to life, the right to education and the right to respect for private and family life were also written into the UK's HRA and are directly relevant to people who have a mental health problem.

Billy and Charlie's presentation then explored their experience of implementing *Respect, Protect, Fulfil*, the SAMH strategy promoting human rights externally and within their service delivery, highlighting some barriers to achieving a rights based focus. They cited two examples for the British Institute for Human Rights (BIHR) report, *The Human Rights Act – Changing Lives*.

One example showed how Article 8 of the HRA (respect for private and family life) had been used to maintain contact between a woman and her children who had been placed in foster care. A lack of staff had been given as the excuse for decreasing contact, but the HRA was used to argue that financial constraint associated with staffing costs was not a viable reason and regular contact was restored. Another example showed how creative thinking can be used to promote human rights. An asylum seeker with post-traumatic stress disorder was unable to access support services because using public transport could trigger a panic attack. If he needed to leave a bus until the attack subsided, he could not afford to board another bus. The individual was then issued with a bus pass, so that he could use transport without fear of costs escalating. Again, the HRA provided the legal basis for a solution.

Billy and Charlie's presentation ended by highlighting the work ongoing in terms of Respect, Protect, Fulfil (further details available from the SAMH website <http://www.samh.org.uk/>) and mentioned that they had submitted evidence to the UN Committee on Economic, Social and Cultural Rights. This Committee is currently assessing the UK's progress to date on implementing the UNCESCR and SAMH's evidence is the first mental health specific contribution the Committee has had.

Gillian Dalley of the Relatives and Residents Association focused on older people, and people in receipt of residential services. There are around 500,000 older people living in care homes in the UK, of whom around 70% have dementia. A major barrier to rights for this group of people is a lack of family and friends with the level of regular contact required to notice a disregard of rights or to offer advocacy. Linked to this is a culture within care homes of residents wanting to avoid fuss and being reluctant to challenge the perceived authority of service providers. Gillian highlighted the vulnerability of this group, who may fear that victimisation or a transfer to another home could follow a challenge. While many care homes offer excellent care incorporating the ethos of human rights, media programmes that focus on scandals can impact negatively on public awareness, further damaging the reputation of good care providers. One remit of the Relative and Residents Association is to empower people to make choices about the care home they select, and provision within it. The Association also provides an advice line where complaints of poor quality care, abuse and neglect are heard.

Data, from the advice line and research conducted by the Association, suggest that care providers can implicitly and explicitly discourage complaints from residents. Specific complaints have revealed neglect (for example pressure sores, untreated heart infection, residents left in own faeces), the removal and destruction of personal property, dehydration and sexual assault. Attempts to complain have sometimes resulted in an abusive reaction from management. Gillian reported examples of residents being given notice to quit a home (either actual notice or the threat of notice) as a punishment. Further, regulators of care homes, for example the Care Commission, have not been keen to be involved in 'local disputes', preferring to regulate the sector as a whole. Since complaints about loss of dignity, of inhuman or degrading treatment, or of a restricted private or family life necessarily originate at the local level, a global strategy seems inappropriate. However, one of the problems facing someone who wishes to complain in a care home is that the only recourse is to make the complaint to the home's management - which is often the very agent responsible for the problem in the first place. Easy access to an external complaints procedure is clearly needed.

Legislation is catching up to protect the rights of adults living in residential care homes. Before the Health and Social Care Act (2008), private sector care homes were not governed by the HRA (for a full discussion see the Briefing Paper for this event, Ferrie, 2009). This new Act now permits the HRA to cover adults who live in private care homes, but only where the placement is funded through local authority funds. Therefore people paying for their care are left outside the HRA. This legislation only covers England and Wales too, so there is concern that Scottish residents will not be afforded the same recognition.

Since some care homes are regulated by inspections only once in every three years, it may be some considerable time before any restriction of human rights is identified. Gillian argued for regular, robust and frequent scrutiny of all care providers, highlighting that the length of a legal challenge has sometimes meant that the individual has died before a resolution was agreed. For an older person making a challenge, the legal system prohibits justice. To sum up, all four presentations argued strongly for human rights to be used to end the vulnerability of people using care provision, used to promote their rights to dignity, to respect and to end degrading and dehumanising treatment.

The Workshops

To optimise knowledge exchange, all presenters and delegates were assigned to one of three small groups of around 10 delegates – with a mix of academics, voluntary sector staff and statutory sector staff in each – for the afternoon workshops. Each workshop was chaired by a member of the organising team, with the assistance of a research student / scribe whose notes have helped us produce this account. A flexible agenda was provided for the two sessions, based around two broad questions: ‘How can the human rights agenda be used to promote dignity and autonomy in care/ residential services?’ and ‘What are the constraints and drivers for the promotion of human rights and dignity in care?’

How can the human rights agenda be used to promote dignity and autonomy in care/ residential services?

The workshops reflected on how a discourse on, and a practical response to, human rights had infiltrated the care sector. One workshop agreed that the term ‘human rights’ is increasingly used, but that practical changes in care provision are slow. A delegate working in a residential home argued that professionals brought personal moral values into their caring role which would integrate well with a human rights discourse, but that for a long time no formal strategic response to human rights existed. The workshops welcomed the shift in thinking but cautiously outlined some of the barriers they had faced in incorporating a rights ethos into care structures.

Training had successfully heightened awareness of rights, and had the benefit of focusing on all levels of professionals, from front line workers, to managers and to organisation leaders. Complications caused by differing definitions of human rights were noted: good practice was sometimes difficult to identify because it was promoted using different language. For example ‘Expert Patient Programmes’ in the health care sector were cited as rights-promoting exercises that were rarely recognised in these terms. It was felt that greater use of the term human rights, in all situations where it could be meaningfully applied, would be helpful. The use of human rights language could make more of a connection with professionals and service users because it was not as abstract or as theoretical a term as other similar words and slogans.

Using human rights consistently to describe all programmes and provisions that incorporated the ethos was encouraged by the workshops. However, some were cautious about the legalistic connotations of the phrase. A human rights discourse was felt to have an adversarial tone, because, in defining a restricted right, necessarily blame had to be placed on some person or body for that restriction. In addition, human rights were viewed negatively in the media, due in part to the legal cases won by prisoners. Where human rights was interpreted as a legal tool, as ‘political correctness gone mad’ or as a feeder to the growing ‘blame culture’, good practice and the true value of the term became obscured. This cultural and media pollution of a human rights discourse was regrettable. There was agreement that the discourse should be harnessed by the ‘deserving’ vulnerable groups to argue for respect and dignity for everyone.

Another significant barrier to implementing a human rights ethos is the tension between it and resources. Though target-setting did not necessarily contradict human rights, it was clear that care providers were not currently doing all they could to eliminate degrading, undignified and dehumanising treatment, and that to do so would require more staff and more money.

There was also real concern that residents in the same home enjoyed different levels of protection under the HRA depending on how they were funded. This could lead to a two-tier service. While it seemed hopeful that a legal challenge could be made to end this loophole, there was general feeling that new legislation was required to force the hand of service providers to act to the benefit of their users.

The target culture has dominated care services leaving providers having to reduce their caring role to practical care tasks to ensure safety, health and hygiene. This culture could be harnessed to facilitate a focus on human rights, if organisations agreed that it was as integral to their aims as balancing books. This shift would involve understanding the need for human aspects of care, for example, factoring in time for staff to talk with residents or users. Many delegates called for greater involvement of service users, to fully explore where rights infringements occurred, and what would be the most efficacious solution.

One focus group felt that the only way a human rights discourse could adequately be adopted, was if it was written into procurement contracts. In this way every organisation within and outwith the statutory sector that was funded by the State (either directly or through public bodies) would need to promote rights in order to fulfil their duties under the contract. Although this strategy was welcomed, some delegates were concerned about how rights could be clearly defined in order to bring about a meaningful shift in the thinking and activities of organisations. It was felt, though, that care provision was increasingly becoming an industry where profit making was paramount. Only if service leaders are forced to value rights, will they develop provision that is compatible with the promotion of human rights.

What are the constraints and drivers for the promotion of human rights and dignity in care?

Although some constraints to the promotion of human rights were discussed in the first workshop session as described above, other constraints and barriers were generated in the second session. One workshop highlighted how close family can also restrict rights, citing an example of a woman who wanted to remain in a particular care home, but was under pressure to move to a home closer to her children to make their visiting easier to manage. While this point was based on an anecdote, several other members of the workshop corroborated the point.

A quite different constraint was identified around the rights of workers. There was consensus that staff needed to have dignity in work, particularly given the low paid and low status nature of most care roles. Front line staff faced difficulty in delivering high quality care with dignity, when they lacked dignity within their own employment. For example, time constraints placed on staff and the need to record care activities performed could undermine the quantity and quality of caring work produced.

Particular concerns were raised in relation to private sector providers, who might employ poorly paid and poorly trained staff, often forced to work alone and unsupervised, thus making it difficult to monitor to what extent service was provided or rights promoted. The poorest service providers placed no emphasis on the continuity of care, not recognising the need for service users, particularly those living in the community, to build up a relationship with their care provider over time.

One workshop felt that for change to occur, and for human rights to be afforded a greater emphasis, then either legislation needed to be tightened or case law needed to provide organisations with an incentive they cannot ignore. Without the threat of a legal challenge, organisations would not comply with the ethos of the HRA.

The media hype around prisoners 'abuse' of the HRA had damaged public opinion on the value of rights. There was some hope that the media could promote rights anew, but others were concerned that the profit-driven media had no incentive to publicise 'worthy' cases. Rather, in order to change public opinion, one workshop suggested that human rights needed to be included within the school curriculum. It may take a generation to have an effect, but the public needed a good working knowledge of the HRA before the Act would generally be supported.

Issues and questions emerging from the closing plenary session

As discussant, **Joanna Ferrie**, Research Fellow at the Strathclyde Centre for Disability Research at the University of Glasgow, noted that the presentations had powerfully promoted the need to build a rights-based approach into all services. Presenters suggested a hopeful future, yet the workshops generated examples of barriers that highlighted the complexity of moving a rights-based philosophy into current provision.

Terminology was certainly an issue and human rights needed to be framed in plain English so that everyone could understand the principles equally well. If rights could be understood as relevant to everyone, the current media standpoint of 'political correctness gone mad' might be eroded. The promotion of rights, if understood fully by all, would not be as adversarial as currently perceived. In addition the current situation of the individual being set against the institution, a consequence of the legal dominance of the terrain, could be replaced by the idea of everyone working together. Within this new model, the rights of employees must also be given due consideration.

There was also a realization that the achievement of human rights is a never-ending journey. In a target culture, the idea that the human rights 'box' will never be definitively ticked, is uncomfortable, but this transition is necessary. The complacency of institutions and their tendency to consider work 'finished' underestimates the task of using the values of human rights and infiltrating all services with these principles.

Though considerable work remains to be done, there was a great deal of energy in the room. Professionals involved in service delivery were now equipped with the fuller understanding and in some cases, the power to influence change. Perhaps this energy will help delegates influence working practices within their own organisations.

Reflections and Future Directions

It was evident that a mapping exercise of Scotland's health and social care services to understand how well rights had already influenced care practices was required. There were concerns that profit margins, targets, low morale amongst staff and a poor complaints/appeals procedure restricted rights. Yet many of these views were based on anecdotal evidence and a more reliable and robust picture of Scotland is urgently required. Further, delegates requested more interpretation of the HRA so that practitioners could easily translate the articles into practical strategies. Case studies and example of best practice illustrating how the HRA has been implemented would also be useful.

References

- BIHR (2008) *The Human Rights Act – Changing Lives* 2nd Edition London: BIHR Accessed at URL: <http://www.bihr.org.uk/documents/policy/changing-lives-second-edition>
- Department of Health (2008) *Health and Social Care Act*. Department of Health. Accessed at URL: http://www.opsi.gov.uk/acts/acts2008/en/ukpgaen_20080014_en_1.htm on 13th May 2009
- Ferrie, J. (2009) *What has Human Rights got to say about Care and Dignity?* Available on the Centre for Research in Education Inclusion and Diversity (CREID) website, University of Edinburgh. Accessed at URL: <http://www.creid.ed.ac.uk/#>
- Office of Public Sector Information (OPSI) (1998) *Human rights Act* Accessed at URL http://www.opsi.gov.uk/ACTS/acts1998/ukpga_19980042_en_1 on 14th May 2009
- Paton, L. (2008) *Handle with Care: A Report on the Moving and Handling of Children and young People with Disabilities*. Edinburgh: Scotland's Commissioner for Children and Young People
- Scottish Government (2003) *Commissioner for Children and Young People (Scotland) Act*. Edinburgh: Scottish Government. Accessed at URL: http://www.opsi.gov.uk/legislation/scotland/acts2003/asp_20030017_en_1 on 14th May 2009
- United Nations (1948) *Universal Declaration of Human Rights*. United Nations Accessed at URL: <http://www.un.org/en/documents/udhr/> on 13th May 2009
- United Nations (1976) *International Covenant on Economic, Social and Cultural Rights* Office of the High Commissioner for Human Rights Accessed at URL: http://www.unhchr.ch/html/menu3/b/a_ceschr.htm on 13th May 2009

Further information

Further information about the project is available from Sheila Riddell, CREID, Moray House School of Education, University of Edinburgh, Holyrood Road, Edinburgh, EH8 8AQ, sheila.riddell@ed.ac.uk.

All Briefings are available in hard copies or as an email or to download on www.creid.ed.ac.uk.

If you would like to receive a briefing, or to be added to, or removed from, the distribution list, please contact Helen Christie (helen.christie@ed.ac.uk)