



# PERSONALISATION AND HUMAN RIGHTS

A Discussion Paper

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## **Contents**

1. INTRODUCTION .....	2
2. THE ROOTS OF PERSONALISATION .....	4
3. POLICY THINKING AND IDEAS.....	6
4. THE EVOLUTION OF PUBLIC POLICY .....	8
5. PERSONALISATION AND HUMAN RIGHTS.....	10
6. RESEARCH AND EVALUATION .....	14
7. PERSONALISATION AND ITS HUMAN RIGHTS DEFICIT .....	16
8. CONCLUSION .....	18

# 1. INTRODUCTION

Scotland is at a significant crossroads in determining the future of its health and social care structures. Potential integration of these services is high on the agenda, and other changes are imminent in the attempt to introduce much greater “personalisation” of the system, through the widespread implementation of the national strategy for self-directed support.

What is the purpose of these changes, however, if not to improve the lives and experiences of individuals, on the basis of a key set of values and principles? What type of care do we want an integrated system of health and social care to provide and how can we ensure sound values and principles are built into the heart of our emerging system?

It can be argued that our current health and social care system lacks explicit guiding principles. The 1968 Social Work Scotland Act is still the primary social care legislation in Scotland. Over forty years on, however, communities and practices have changed considerably and there is a need to consider whether the principles implicit in the legislation continue to apply. The most significant amendment to the 1968 Act has been the NHS and Community Care Act 1990, which created a mixed economy of care and a purchaser and provider split. It is arguable that social care in Scotland now needs to develop a modern, coherent values base to fit with new structures and expectations.<sup>1</sup>

It is these clear, shared values and principles that should govern approaches to integration and the way we build new structures that will empower the citizens of Scotland and unlock them from the failings of past systems, rather than locking them into a new system that lacks a clear vision.

The purpose of this paper therefore is to provide an outline of this vision, and of the values that should drive our new system of care. It is our contention that we have an opportunity to lead the way forward by placing a renewed emphasis on human rights at the very heart of a personalised system of care and support.

In this paper we will argue that the broad policy concepts and detailed practice of personalisation are rooted in, and informed by, human rights: both with regard to the general approach human rights imply and the underpinning legal framework they provide.

It is further argued that a current Scottish manifestation of “personalisation” - the national Self-Directed Support Strategy together with the associated legislation in progress – creates a solid platform to build

on and should be implemented locally in such a way that the human rights principles that lie at its core are clearly evident in the lives of individual men and women.

## 2. THE ROOTS OF PERSONALISATION

Some of the roots of personalisation are found in the disability, mental health survivor and service user movements of the 1970s. Their origins can therefore be discerned in the emergence of the *independent living movement* and the articulation of the social model of disability.

Key principles and values of this movement are:

- Independent living
- Participation
- Control
- Choice and empowerment

The independent living movement in Scotland now increasingly frames its work in human rights terms and recognises that independent living requires the respect, protection and fulfilment of all human rights, covering as they do every aspect of an individual's life – at work, at home and in the community.<sup>2</sup>

Personalisation also owes its origins, at least in part, to the values and principles of the *social work profession*. The philosophy informing personalisation is thus familiar to us: “putting the individual first”, “respect for the individual”, and “self-determination” have long been at the heart of social work.

**BASW states in its code of ethics (BASW, 2002) that social work is committed to the five basic values of:**

- Human dignity and worth
- Social justice
- Service to humanity
- Integrity
- Competence

A more recent influence on personalisation policy in the UK has been the practical work of In Control, a social enterprise established in 2003, and its pioneering of *self-directed support* and individual budgets as ways to reform

the social care system.

A Scottish manifestation of this work can be found in the Scottish Government's incorporation of self-directed support ideas and principles within its plans for the modernisation of the system of direct payments.<sup>4</sup>

## 3. POLICY THINKING AND IDEAS

The specific articulation and definition of the term “personalisation” begins with *Charles Leadbeater* in 2004.<sup>5</sup> Building on the influences described above, he stresses the importance of the direct participation of the people who use services:

*By putting users at the heart of services, by enabling them to become participants in the design and delivery, services will be more effective by mobilising millions of people as co-producers of the public goods they value.*

Leadbeater argues that personalised public services can mean at least five different things:

1. services that are more customer-friendly;
2. services that give people who use them more say in how they are run;
3. services that give people a more direct say in how money for services is spent;
4. services that co-opt the people that use them as co-designers and co-producers;
5. enabling society to organise itself.

The last two meanings represent a more significant and substantial understanding of personalisation, where the emphasis is less on modifying existing services, and more on the transformation of whole service systems and the way people work together.

Emerging from Leadbeater’s work, the term “co-production” has gained more recent currency as a way of talking about sharing power and knowledge in social care services in the UK. It has also been called “co-creation” or “co-design”.

It places importance on:

- frontline workers focusing on people’s abilities rather than seeing them as problems<sup>6</sup>;
- increased levels of power and resources being shared with people on the frontline – people who use services, carers and frontline workers<sup>7</sup>;
- people who use services as assets encouraged to work alongside

professionals as partners in the delivery of services.

## 4. THE EVOLUTION OF PUBLIC POLICY

In the years following the publication of Leadbeater's work, personalisation has become a major aspect of governmental agendas for public sector reform, with personalisation defined by the UK Government as:

*The process by which services are tailored to the needs and preferences of citizens. The overall vision is that the state should empower citizens to shape their own lives and the services they receive.<sup>8</sup>*

In *Scotland*, the publication in 2006 of the Government-commissioned "Changing Lives: report of the 21st Century Social Work Review"<sup>9</sup> evidenced a strong commitment to the principle of personalisation in shaping the future of social work:

*Personalisation is driving the shape of all public services, with a growing public expectation that services will meet their needs, helping them achieve personal goals and aspirations.....To be effective in meeting that challenge, social work services will need to engage individuals, families and communities and to work in new ways with other parts of the public sector, focusing increasingly on prevention.*

*As demanding consumers of goods and services, users of public services will increasingly expect the same variety, choice and flexibility that they expect from the business sector. They will demand a more personalised approach, much greater involvement at all levels and more transparency about the level of services available. Because people are becoming better informed they have growing expectations that services will be delivered where and when they want them.*

*The recommendations we set out in this report will therefore provide the foundations for more personalised services, including:*

- *a greater focus on prevention;*
- *approaches to delivery across the public sector and partners in the voluntary and private sectors;*
- *flexible service delivery;*

- *more effective use of social work skills;*
- *more empowered users of services;*
- *increased community capacity.*

Personalisation is no longer only the domain of social work and social care. The Government's NHS Quality Strategy has person-centred care as a main theme and there is a clear desire to ensure that personalisation of health care evolves from this. The integration agenda offers a unique opportunity to merge this thinking around clear values and principles.

## 5. PERSONALISATION AND HUMAN RIGHTS

As stated in the preamble to the Universal Declaration of Human Rights (1948) human rights are based on a:

*recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family [and that] [a]ll human beings are born free and equal in dignity and rights.*

The legal underpinning of human rights seeks to ensure that in practice we are all able to live the lives we choose to live, and participate equally in the communities in which we live, regardless of our status in society.

Human rights-based and person-centred approaches therefore share the same starting point - the personal experiences of the individual - and the same end goal - empowering individuals to fulfil their potential by giving them the authority, capacities, capabilities and access needed to change their own lives, improve their own communities and influence their own futures.

Nonetheless, despite the origins of the concept of personalisation being traceable to the activist history of the disability movement, and the assertion of the rights and freedoms of previously marginalised groups, the more recent articulation of the idea as a public policy places relatively little emphasis on human rights. There is a clear concern to improve whole systems of public services, social and health care by placing the individual at their centre, but without an attendant or consequent stress on the human rights of that individual. There is much discussion of the importance of people who use services participating more, working alongside professionals as equals, being empowered and having increased levels of self-determination. But there is little in the literature of personalisation that confirms the legal basis for these increased level and types of entitlement.<sup>10</sup>

### The Legal Basis of Personalisation: both means and ends

This is not to say that such a legal basis does not exist. The European Convention on Human Rights (ECHR), incorporated into domestic law through the Human Rights Act (1998), and the Scotland Act (1998), as well

as the international human rights treaties signed and ratified by the UK, provide a legal underpinning to the concept of personalisation.

Furthermore, building on these legal obligations, a human rights-based approach to the development, design and delivery of services means putting human rights considerations, and therefore the participation of the individual, at the centre of all policies and practices.

Human rights are seen therefore both a means of doing things, driven by human rights standards and principles, as well as an end to be achieved.<sup>11</sup>

## The Right to take part

Everyone has the right to participate in decisions which affect their human rights. A human rights-based approach requires a high degree of participation of rights holders in the development of policy and practice, as well as the involvement of affected communities, civil society and others. According to the International Covenant on Civil and Political Rights<sup>12</sup> (ICCPR, Article 25) people have a right to participate in decisions which affect the realisation of their human rights.<sup>13</sup> The Convention on the Rights of Persons with Disabilities (CRPD)<sup>14</sup> also contains several protections of the right to participate in decisions and access to support for participation and access to information.<sup>15</sup>

## The Right to a private, home and family life and to access information

Article 8 of the European Convention on Human Rights<sup>16</sup>, the right to respect for private and family life, home and correspondence, includes a right to informed consent to limitations of human rights and to participation in decisions which affect human rights. The European Court of Human Rights has stated that this right encompasses, among other things, “the right to personal autonomy, personal development”<sup>17</sup> and the right “to conduct one’s life in the manner of one’s choosing”.<sup>18</sup>

The right to information is also a component of the right to freedom of expression<sup>19</sup> and increasingly recognised as a freestanding right to information in a form and language which enables an individual to participate in decisions which affect their human rights. This includes the right to accessible information for people with disabilities. CRPD Article 9(2)(f) requires the promotion of “other appropriate forms of assistance and support to persons with disabilities to ensure their access to information”.

## The Right to Live Independently and Be Included

Article 19 of CRPD also asserts the right to live independently and to be included in the community. This means disabled people have the right to the same choice and control as non-disabled people and Governments should do everything they can to ensure that disabled people enjoy these rights. It should also be emphasised that the realisation of Article 19 is seen as being interdependent with other articles in the Disability Convention, for example the right to personal mobility, health, work and employment, social protection, participation in public life etc.<sup>20</sup>

Choice and control are key elements, therefore, to the realisation of this full set of rights.

## No Exceptions

The ECHR also prohibits discrimination on any ground, such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.

This means provision of services must be assessed for indirectly discriminatory impacts when there is a failure to treat differently persons whose situations are significantly different without an objective and reasonable justification.<sup>21</sup>

The requirement for non-discrimination, together with a human rights based approach to issues of capacity under, for example, Article 12 of the Disability Convention, ensure that personalisation is an approach for all individuals regardless of status and not contingent upon meeting certain criteria.

It can be seen, then, that human rights protections lend considerable weight to the arguments for choice, participation, involvement and transparency in the way in which services are both designed and delivered.

There is significant scope for the Convention rights in the Human Rights Act to be better understood and applied more consistently to advance the personalisation agenda. As the European Court of Human Rights has repeatedly stated “the very essence of the Convention is respect for human dignity and human freedom”<sup>22</sup> and rights such as Article 8 extend to “aspects of an individual’s physical and social identity including the right to personal autonomy, personal development and to establish and develop relationships with other human beings and the outside world”<sup>23</sup> as well as “to conduct one’s life in a manner of one’s choosing”.<sup>24</sup> A personalised approach, centred

on the participation of the individual is necessary for the full realisation of these rights.

## 6. RESEARCH AND EVALUATION

Independent research based on evaluation of the Scottish Human Rights Commission’s “Care about Rights” project demonstrates the value that a human rights-based approach can bring to care and support services.<sup>25</sup> Around 800-1,000 care workers and managers around Scotland have received human rights training using the “FAIR” model - a process of human rights-based decision making based on analysis of the following four steps:

### 1. Facts:

- What is the experience of the individual?
- Is the individual being heard and, if not, do they require support to do so?
- What are the important facts to understand?

### 2. Analysis of rights at stake:

- What are the human rights or issues at stake?
- Can the right be restricted?
- If so, what is the justification for restricting the right?
- Is the restriction ‘proportionate’? i.e. is it the minimum necessary restriction to meet the aim or is it a “sledgehammer being used to crack a nut”?

### 3. Identification of responsibilities:

- What changes are necessary?
- Who has responsibilities for helping to make the necessary changes?

### 4. Review of Actions:

- Have the actions taken been recorded and reviewed and has the individual affected been involved?

The research strongly indicates that using this approach assists social care

workers to involve service users and families in their decision-making and deliver more personalised services, thereby helping to shift the power dynamic in relationships between services and the people for whom they work.

The responses to the follow-up survey to the training indicated that 53% of respondents reported that “Care about Rights” had helped them improve the way service users, their families and carers are involved in decision-making, and a further 29% expected this would happen in the future.

**One respondent commented:**

*FAIR helps focus the minds and actions of ourselves and fellow professionals on the needs of an individual service user. This has helped us to accept that, perhaps sometimes, we were part of the problem and to access the support we needed from other professionals.*

**A case study example in the report illustrated how the FAIR approach had assisted with a more personalised approach:**

*A Staff Nurse commented that she has used FAIR when developing care plans to make sure residents are involved. For those who do not have capacity to be involved, the FAIR framework ensures that a carer or advocate is involved on behalf of the older person. In many cases the final care plan may not look much different than it would have in the absence of Care About Rights training and FAIR, however, Care About Rights is perceived to have improved the process and put in place a framework that helps ensure that individual rights are met and points of view are sought and heard. She feels this has enhanced the care plans.*

Similarly, an independent evaluation of the experience of a Special NHS Board, which has sought to adopt a human rights culture, demonstrated how the participation of patients in decision-making had led to better staff and patient engagement, increased work-related satisfaction amongst staff, and increased satisfaction amongst patients over their care and treatment.<sup>26</sup>

## 7. PERSONALISATION AND ITS HUMAN RIGHTS DEFICIT

To date, however, the framework of rights as set out above has not been central to the development of personalisation as a key driver of public policy. As a consequence, much of the new autonomy proposed through personalisation has the feel of a set of “privileges” that can be variously afforded, denied or withdrawn by professionals acting on behalf of the state through the apparatus of local government.

Leadbeater himself anticipates this difficulty in a paper commissioned by the 21st Century Social Work Review in Scotland<sup>27</sup>:

*“A version of personalisation is already the goal of the Scottish social care system. But it is a goal the system fails to reach consistently. The 1968 Social Work Scotland Act, which inaugurated modern generic social work, set the goals of social work that most social workers still ascribe to today ...”*

*“Yet the testimony of both professionals, care staff and clients is that the social work system often fails to deliver on these goals. In practice social workers seem to be risk managers and resource allocators, gatekeepers and controllers, often working with clients in crisis when the task is to save them from harming themselves or others ...”*

*“... our workshops and interviews with service users also uncovered a feeling among many that the service they receive is driven not by what people need but by what the system can deliver: **it feels as if the professionals and system make all the decisions that count. Many of the clients feel as if the professionals are in charge and they have no choice** [our emphasis]. Social work is formally committed to deliver a set of goals – which embrace the ideals of person centred support – and yet the system works to a completely different logic to control risk and resources.”*

The Social Care (Scotland) Self-Directed Support Bill is intended to empower more people in Scotland to direct their care - to have informed choice and control about how their support is provided - and therefore

represents a major opportunity to bring about transformational, “personalised” change. There is a risk, however, that unless deliberate steps are taken to address the human rights deficits and power imbalances documented here, there will be too narrow a focus on the system and process changes required to implement the mechanisms of self-directed support; and existing managerial and clinical models of service delivery will persist.

A criticism sometimes expressed about the personalisation agenda is that its emphasis on the individual having control and choice is overly individualistic and that state and collective responsibility for safeguarding an individual’s rights, or the rights of others, such as those of a largely unregulated workforce, is diluted or lost. A human rights-based approach is also helpful in addressing these issues, providing a framework of responsibilities which places the individual’s choice and control at the centre of decision making while balancing this with responsibilities to safeguard the individual from harm, the broader public interest and the rights of others.

A possible remedy for the human rights deficit was anticipated in the field of dementia with the assertion of a national “Charter of Rights”<sup>28</sup>, which points the way towards the type of proactive intervention that may be required more generally. Similarly, there would seem to be considerable merit in urging all those with responsibility for the development of the Scottish social care workforce to establish the understanding of a person-centred human rights-based approach as a non-negotiable core competence; and in this way seeking to assure the quality of practice in this regard, rather than simply assuming that it already exists.

## 8. CONCLUSION

The contention of this paper is:

- that there is a need to restore human rights to the very centre of our system using personalisation as a mechanism – working alongside each individual man, woman or child using the public services concerned;
- that only in this way will the conflicts of interest that currently distort personalisation be removed, and the balance of power between the citizen and the state be restored; and
- that this type of rebalancing requires a deliberate course of action to be adopted by central and local government alike.

The paper is offered as a focus for discussion and debate on the issues raised, and we invite all stakeholders to involve themselves urgently with this agenda.

## ENDNOTES

- <sup>1</sup> A Tale of Two Reports: Social Work in Scotland from Social Work and the Community (1966) to Changing Lives (2006) Ian Brodie, Chris Nottingham and Stephen Plunkett Br J Soc Work (2008) 38 (4): 697-715.
- <sup>2</sup> On 8 December 2009, the Scottish Government, the Convention of Scottish Local Authorities (COSLA) and the Independent Living in Scotland (ILiS) Steering Group signed a Shared Vision for Independent Living in Scotland. In 2010 NHS Scotland became the fourth signatory. That Vision clarified that Independent Living is about choice, control, freedom and dignity, that it covers every aspect of an individual's life – at work, at home and in the community, and established a model of “co-production” with each signatory an equal partner in an Independent Living Core Reference Group (CRG). The CRG operates across government and is co-chaired by the Scottish Government Director for Strategy and Performance and the Convener of the ILiS Steering Group.
- <sup>3</sup> BASW (British Association of Social Workers) (2002) The code of ethics for social work. BASW, Birmingham.
- <sup>4</sup> Self-Directed Support: A National Strategy for Scotland. February 2010
- <sup>5</sup> Leadbeater, C (2004b) Personalisation through participation: A new script for public services. Demos, London.
- <sup>6</sup> Boyle, D, Clark, S and Burns, S (2006) Co-production by people outside paid employment. Joseph Rowntree Foundation, York.
- <sup>7</sup> Boyle, D and Harris, M (2009) The Challenge of Co-production: How equal partnerships between professionals and the public are crucial to improving public services. NESTA, London.
- <sup>8</sup> Prime Minister's Strategy Unit (2007) HM Government policy review: Building on progress: Public services. HM Government, London.
- <sup>9</sup> Report of the recommendations made by the 21st Century Social Work Review Group for the future of social services in Scotland, February 2006.
- <sup>10</sup> The Long-term Conditions Alliance Scotland (LTCAS) publication, Living well with long-term conditions, Twelve propositions for social care, prepared by Jim McCormick of the Joseph Rowntree Foundation explicitly recognises the case for embedding human rights in health and social care stating “Taking a rights-based approach to social care doesn't get us off the hook of making hard choices on resource allocation, but it does offer more fertile ground in which to embed progress.
- <sup>11</sup> The FAIR methodology, developed by the Scottish Human Rights Commission and applied in care settings in the Commission's Care about Rights project demonstrates this approach in practice. <http://www.scottishhumanrights.com/careaboutrights/flowchart>.
- <sup>12</sup> The UK has been a party to the UN ICCPR since 1976 The Human Rights Committee has found that individuals have the right to participate in decision-making which may affect the realisation of their rights in e.g. Apirana Mahuika et al v New Zealand (CCPE/C/70/D/547/1993).
- <sup>13</sup> Interpreted to cover “all aspects of public administration, and the formulation and

implementation of policy”, Human Rights Committee, General Comment No. 25.

<sup>14</sup> The UK became party to the UN Convention on the Rights of Persons with Disabilities in 2009.

<sup>15</sup> e.g. CRPD, Article 4 on general principles; article 21 on access to information; article 26 on support for participation; article 29 on right to participate in public life.

<sup>16</sup> The UK has been a party to this convention since 1953. Most of the rights in the convention were incorporated into the law of Scotland by the Human Rights Act 1998 and the Scotland Act 1998.

<sup>17</sup> *Evans v UK* 2007, Grand Chamber, citing *Pretty v UK* (2002).

<sup>18</sup> *Pretty v UK* (2002).

<sup>19</sup> Article 10, ECHR; Article 19 ICCPR; Article 21 CRPD.

<sup>20</sup> E.g. UN CRPD article 9 on accessibility; article 12 on legal capacity; article 13 on access to justice; article 18 on liberty of movement; article 20 on personal mobility; article 24 on education; article 25 on health; article 27 on work and employment; article 28 on adequate standard of living and social protection; article 29 on participation in political and public life; article 30 on participation in cultural life, recreation and sport.

<sup>21</sup> *Thlimmenos v. Greece*, 6 April 2000, Application No. 34369/97.

<sup>22</sup> *Pretty v UK* (application no. 2346/02) Grand Chamber judgment of 29 April 2002, para 65; *Christine Goodwin v. the United Kingdom*, (application no. 28957/95), Grand Chamber judgment of 11 July 2002, paras. 71 and 90.

<sup>23</sup> *Evans v UK* (application no. 6339/05) Grand Chamber judgment of 10 April 2007 at para 57; citing *Pretty v UK* (application no. 2346/02) judgment of 29 April 2002.

<sup>24</sup> *Pretty v UK*, *ibid*, para 62.

<sup>25</sup> Care about Rights Project Evaluation, Phase 2 Report to the Scottish Human Rights Commission, GEN, the University of Bedfordshire and Queen Margaret University, October 2011.

<sup>26</sup> Human Rights in a Health Care Setting: Making it Work - An evaluation of a human rights-based approach at The State Hospital <http://www.scottishhumanrights.com/application/resources/documents/HRHCSFINALVERSION.pdf>.

<sup>27</sup> *Personalisation and Participation: The Future of Social Care in Scotland*, Final Report, November 2005, Commissioned by Care 21 for the Social Work Review: Charles Leadbeater and Hannah Lownsbrough.

<sup>28</sup> *Charter of Rights for People with Dementia and their Carers in Scotland: stepping out of the shadows*”, Scottish Parliament Cross-Party Group on Alzheimer’s (2009).

## ABOUT US

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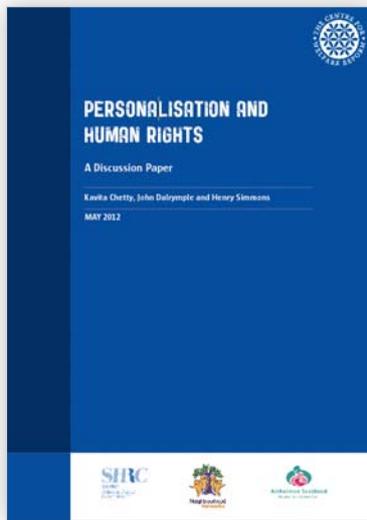
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