The Challenge of Dignity in Care

Upholding the rights of the individual
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A report for Help the Aged by Ros Levenson
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The Help the Aged challenge

Dignity is a word much used, seldom interpreted and too rarely experienced by older people when they need care. Help the Aged believes the time has come for us all to declare our commitment to reversing this state of affairs. This report is our contribution to what we hope will be a determined and sustained drive to raise standards of care and behaviour. It is our own Dignity Challenge.

A decade or so ago we uncovered a quiet outrage, of modern hospitals delivering archaic care, of professional care workers acting in an uncaring and often inhuman way, of sophisticated health services not even delivering on the basics of toileting, mealtimes and communication. Our Dignity on the Ward campaign attracted widespread public support then, for the very significant reason that it rang true to people’s experiences. And it led to some change for the better, in the shape of the welcome and well-constructed National Service Framework for Older People in 2001.

So now, after ten years of initiatives, reorganisations, plans, targets and frameworks, where do we stand? As the debate turns to how we can exploit the array of modern technologies and opportunities in front of us – poly pills, remote sensors, shared electronic records and many other such innovations – surely we have moved beyond the basics, the mere minimum entitlement in any decent society?

Too often the answer is no. Whether you look at the recent Healthcare Commission’s surveys of dignity and respect, powerful campaigns such as Age Concern’s Hungry to be Heard on malnutrition in acute care, the Commission for Social Care Inspection’s observation of routinely rushed home care visits, or at the evidence we have assembled in this report, it is clear that dignity is denied to many of our citizens at a perilously low point in their lives. And now the Joint Committee on Human Rights, an authoritative parliamentary body, reports comprehensively and critically on the denial of human rights to older people receiving healthcare.

All this follows a massive industry of policies, protestations and political slogans that has made dignity an over-familiar ‘hurrah’ word, along with motherhood and apple pie. It is too easy to deploy the word promiscuously. This report sets out the multi-faceted meaning we believe dignity has, encompassing not just those well-known rudimentary aspects of care which are so often neglected, but also the dignity inherent in treating people as human beings, and to carry on living life to the full, especially in the context of people receiving care. This is the true, rich nature of dignity. It is vital that those doing the caring embrace this wide definition.

The following story, told to Help the Aged during recent work on end-of-life care, illustrates how, in the midst of the care environment, the concept of dignity can be overlooked.

Jack died, in the end, of a lung infection. But what in fact killed him was a combination of Parkinson’s disease, severe arthritis, enlarged prostate and a damaged heart. During the year and a half of his final illness, he was treated by three sets of specialists for these different ailments and was shunted back and forth between three different hospitals as each [ailment] in turn was attended to. As a result, his notes were frequently lost or delayed or sent to the wrong hospital, he often spent days, even weeks, without being treated at all, and he invariably lost out on the care of the ailments that weren’t that particular hospital’s speciality.

The problem was that while there were lots of people in charge of different parts of Jack’s body, none was in charge of Jack.

Help the Aged believes that the following domains serve as manageable framework for understanding dignity:

- personal hygiene
- eating and nutrition
- privacy
- communication
- pain
autonomy
personal care
end of life
social inclusion.

In our report we explore each of these in detail, taking stock of the plentiful evidence and commentary that already exists.

Being clear about what we mean by dignity is essential. But the whole point of clarity is to be able to build on that foundation and set a realistic direction. We must look ahead and focus on concrete areas of improvement. We seem currently to be stuck in a cycle in which the occasional tabloid horror story triggers outraged comment, popular revulsion, campaigning challenges, political ‘back-foot’ reaction, but little sustained attention to improvement.

Help the Aged is developing a method of measuring progress across each of these key aspects of dignity. We are doing this not from the outside, pointing the finger, but working with the regulatory agencies, the Government and other bodies to achieve a sense of shared understanding and purpose. We are using academic partners to inform this work.

Our aim is to provide a basis for us all to use in working towards steady improvement over time. Later in 2007 we will publish the framework of measures, the current state of play against each measure, and our own proposed targets for improvement. We will revisit the measures at regular intervals to establish whether, in fact, dignity in care is becoming more common, and we will publish our conclusions.

We are realistic about the pace of change. Attitudes, practices and cultures are deep-rooted and do not change in response to a one-off campaign or imperative. There are enabling steps which need to be taken straight away. As we go to press, the Government is pondering whether older people should be entitled to the same degree of legal protection and empowerment as other potentially disadvantaged groups in society. Why ponder any more? Why not act now? Why should some be less equal than others – unless we are prepared to accept a world in which dignity and equality are unevenly shared?

Help the Aged also acknowledges that the experiences of the many people we hear from are the minority. There are many unacceptable cases, but there are many, many more where care is of the highest order, and where professionalism is coupled with compassion.

The challenge for the UK, so rich in economic, specialist, knowledge-based and societal resources, is that one violation of an individual’s right to be an individual is one too many. This is the challenge Help the Aged presents to you in this report.

Paul Cann
Director of Policy and External Relations
Help the Aged
1 Introduction

Everyone claims to be in favour of dignity in the care of older people although there is no single agreed definition of what it consists of, and little consensus on how to assess it. This report aims to revisit the concept of dignity in care and to make a contribution to the growing discussion about what dignity in care means to older people, and how dignity can be measured in the context of health and social care.

The report will look at a number of previous attempts to define dignity in the recent past and will examine the policy context and some of the significant documents in which statements about dignity have been made, in order to see whether there are common themes. The report will also review what is known about some aspects of care for older people where dignity is most often seen as critically important. While we do not claim to cover all aspects of dignity, or to review all the evidence about dignity in relation to the aspects that we identify, we assert that recurrent themes are identifiable. Using these themes as a basis, we put forward a statement of principles on which dignity in care should be based and set out some thoughts on how metrics can be developed in a more person-centred and human rights-based way than has been the case up to now.

Dignity in care is about how people feel when receiving care. For that reason, dignity in care cannot be fully achieved without a wider campaign for dignity in old age. But there is a great deal to be done specifically on dignity in care as part of that wider campaign. Help the Aged is now in a good position to work with older people to further define meaningful metrics for dignity, and to investigate how far the essential ingredients of dignity are actually part of the experiences of older people who use care services.

We start from the premise that dignity is an inalienable right. It is not something that can be given to older people in care so much as something that must not be compromised or diminished in the health care system. It is a sobering thought that in 2007 dignity in care has not yet been fully achieved, but there is much good practice to build on and no shortage of ideas for sustainable improvements.
Dignity: a general hurrah word

One of the problems of defining dignity is that it has become a ‘hurrah word’ – a term of general approval, to which no one can object. So for service commissioners and providers, dignity is often cited rather loosely as an essential ingredient of the services they provide, or something they aspire to assure more robustly in the future. They can be quite sure that no one will say that it is not necessary to consider dignity as a matter of importance. Similarly, service users in general, including older people, frequently use ‘dignity’ as a broad signifier of a service that they find appropriate in a variety of ways. Conversely, services that fall short of expectations in all kinds of ways are often castigated for not promoting dignity.

To some extent, this general, but undefined, sense of dignity is of use. It is, indeed, difficult to define the essential elements of dignity, and the precise ingredients may differ from one person to another. For example, some people feel that their dignity is compromised if they cannot wear their own nightclothes in hospital, while others may feel that their dignity is adequately maintained if they are provided with nightclothes that are clean, comfortable and decent. However, if dignity is seen only as a subjective concept it becomes difficult, or even impossible, to agree on how care services can be organised to maximise and promote dignity. It is impossible to assess how far services are succeeding in maintaining and promoting dignity if there is a lack of consensus on what the word means.

2 Definitions of dignity
Definitions of dignity

Privacy and dignity

Privacy has been defined as ‘freedom from intrusion’ (Department of Health 2006f). Often, the term ‘privacy’ is put together with ‘dignity’ as though the two concepts are essentially the same. While there is considerable support for seeing privacy as an essential aspect of dignity (and, indeed, an essential aspect of it for many people), to conflate these two terms results in a loss of focus on the many other aspects of dignity that are important to service users of all ages, including older people, who as significant users of health and care services are often most affected by the presence or absence of dignity in care.

Definitions of dignity in recent use

Writing in the *Nursing Standard*, a nurse notes several different definitions of dignity. Included among these are the quality or state of being worthy, honoured or esteemed and feeling and being treated as a human being in a non-judgemental environment. Respect, personal and privacy were the words most frequently used to describe dignity (Birrell, J. et al 2006).

A recent European project (Tadd, W. 2004; Dieppe, P. undated) looked at dignity and older people across six countries:

- UK
- Ireland
- Spain
- Sweden
- Slovakia
- France.

As part of this project, up to 20 focus groups of 4–6 people were held in each participating centre. In all, 89 focus groups were held, involving a total of 391 older people. Interestingly, despite a wide range of backgrounds, there was a substantial level of agreement about the meaning and experience of human dignity in the lives of participants. However, like many researchers before them, they found that it was easier to identify situations when dignity was lacking rather than identifying either when it was present, or what it meant. The researchers in this project used a model which identifies four types of dignity:

- **dignity of merit** – i.e. linked to role or position in society, dependent on economic and social position
- **dignity of moral status** – i.e. emphasises importance of the person’s moral autonomy or integrity
- **dignity of identity** – related to self-respect, and reflects an individual’s identity as a person. Can be violated by physical interference, or by emotional or psychological insults such as humiliation. This type of dignity is most relevant in the context of older people
- **Menschenwürde** – i.e. the inalienable value of human beings.

The report of the focus groups that took place in the UK as part of this project (Dieppe, P. undated) concluded that dignity is a salient concept and central to the concerns of older people. It stated that policy issues should focus on the main themes cited by older people such as respect, communication, autonomy, rights and equality.

Many writers and commentators on dignity have noted the lack of an agreed definition, and they have often taken a pragmatic view, sometimes deciding to use common dictionary definitions. For example, a recent practice guide from the Social Care Institute for Excellence (SCIE) (Social Care Institute for Excellence 2006) states:

_Dignity consists of many overlapping aspects, involving respect, privacy, autonomy and self-worth. The provisional meaning of dignity used for this guide is based on a standard dictionary definition: a state, quality or manner worthy of esteem or respect; and (by extension) self-respect. Dignity in care, therefore, means the kind of care, in any setting, which supports and promotes, and does not undermine, a person’s self-respect regardless of any difference._

This definition appears to be wide enough to encompass many diverse features of dignity, while being specific enough to be of some value...
as a basis for dignity metrics. However, it must be supported by a varied menu of dignity components, which we discuss in Section 5. Like any other menu, some individual users will prefer some items to others. However, the dignity menu should include a very wide range of items, all setting high standards, so that individual and cultural preferences can be met.

We also note, as does SCIE, that:

*While 'dignity' may be difficult to define, what is clear is that people know when they have not been treated with dignity and respect.*

Dignity is certainly integral to some of the human rights principles enshrined in the European Convention on Human Rights and incorporated into our law by the Human Rights Act 1998. Mr Justice Munby, giving judgment in a case concerning two profoundly disabled adults, described ‘physical and psychological integrity’ as part of the private life of an individual protected under Article 8 of the Convention (right to private and family life). He went on to say that human dignity is at the core of both Article 8 and Article 3 (prohibition on torture, inhuman and degrading treatment).
Dignity in care: not a new concern

Dignity in care is by no means a new feature of the policy landscape in the United Kingdom. There has been a proliferation of reports, edicts, circulars, guidance and toolkits on dignity over a number of years. Some of these have taken place in response to reports of abuse, media campaigns and campaigns from organisations such as Help the Aged.

Many of the reports and policy statements have noted recurrent lapses in dignity in a range of care settings and the suggested remedies for the problems which have often been put forward have shown similarities over a long period. In many areas there has been good progress, but that progress has not been even. The recurrence of some concerns in the literature and in evidence from older people leads to the conclusion that it has sometimes been ‘two steps forward, three back’. The fact that repeated efforts and initiatives to improve dignity have not been more successful or sustainable, in spite of some very significant improvements, remains something of a mystery.

This situation persists right up to the present. The Healthcare Commission’s most recent annual staff survey asked staff if they believed patients were the top priority for their trust: 45 per cent agreed and 26 per cent disagreed, the latter figure rising five percentage points since the previous survey. Staff were also asked whether they would be happy with the standard of care provided in their trust if they were a patient: 39 per cent agreed and 27 per cent disagreed (Healthcare Commission 2007b). Of course, dignity would not have been the only factor influencing staff responses, but it is reasonable to infer that it is part of the picture.

In the Appendix we look at the policy context in which concerns about dignity in care have developed. We consider some of the key documents that make up the policy context in which dignity has been examined and is being taken forward. While this is not intended to be a definitive summary (for example, it does not review the many documents that support a sustained move towards care outside institutions and a shift towards care nearer to home), it aims to illustrate the longevity of dignity-related issues as a matter of public concern and the apparent intractability of tackling shortfalls in dignity in care services. For the sake of clarity, various documents and initiatives have been described separately, but it should be borne in mind that this does not imply a linear development. Many of the initiatives cross-fertilised and influenced each other, and continue to do so.

See Appendix for discussion of:
- the Help the Aged ‘Dignity on the Ward’ campaign
- Not Because They Are Old (HAS 2000 report)
- Essence of Care (practitioners’ benchmarking tool)
- National Service Framework for Older People
- A New Ambition for Old Age (Department of Health report)
- Living Well in Later Life (report by the Healthcare Commission et al.)
- National Minimum Standards for Care Homes and Domiciliary Care
- Standards for Better Health (Department of Health)
- Dignity in Care public survey, 2006
- The Dignity Challenge, 2006 (government campaign)
- dignity in care and human rights.
Looking at the policy context, the mountain of papers and toolkits on dignity and the repeated failure of successive attempts to secure dignity in care for older people leads to the inexorable conclusion that just issuing commands to improve dignity in care is likely not to be wholly successful. That is why we set out some principles that underlie dignity in care. These principles are explicit or implicit in the material reviewed for this document. They are not intended to replace formal assessments and metrics for dignity in care (all of which are in great need of further development), but to complement them.

We suggest the following principles, which are listed here and then discussed briefly below:

1 Dignity in care is inseparable from the wider context of dignity as a whole

2 Dignity is about treating people as individuals

3 Dignity is not just about physical care

4 Dignity thrives in the context of equal power relationships

5 Dignity must be actively promoted

6 Dignity is more than the sum of its parts

Dignity in care is part of a wider understanding of dignity. Although there are many good reasons to focus on dignity in care (since older people are at their most vulnerable to loss of
dignity when they are dependent on others for care), a sense of dignity draws on factors that are not directly related to care. Ageism in society as a whole, a culture that undervalues, fears or despises old age, a culture where old age is a subject for ridicule rather than celebration – these are all factors that need to be addressed before we can become fully optimistic that dignity will be omnipresent in the care context. This means that the broader fight for age equality is one of the keys to promoting dignity in care. We need to go beyond dignity in care and embrace a much broader concept of the dignity of old age.

2 Dignity is about treating people as individuals

Dignity means different things to different people and possibly different things to the same person at different stages of their lives. Individuals change and so does the social context in which we live, so that what is acceptable at one point may be unacceptable at another. This means that flexible, person-centred care – often talked about but not always delivered – must remain a central tenet of dignity in care.

3 Dignity is not just about physical care

The literature on dignity tends towards a concentration on physical care. Clearly, physical care is fundamentally important. If a person is hungry, dirty, uncomfortable or in pain, they will not have a sense of dignity. However, if their physical needs are taken care of but their emotional, psychological, religious or spiritual needs are overlooked, dignity will not be possible.

4 Dignity thrives in the context of equal power relationships

Power differentials are rarely explicitly addressed in the context of dignity, but that does not mean that they are unimportant or that they are unrecognised by people who receive health and care services. Power differentials manifest themselves in all kinds of ways. For example, if an older person is asked to wait in a state of undress so that a busy health or social care professional does not have to wait while they prepare themselves for examination or care, that may tell a story about who is the most powerful person in that interaction. If a doctor is known by his or her professional title (Doctor, Professor, or whatever) but the person receiving treatment or care is known by a first name, that too may indicate a power differential.

Most conclusively, the insecurity that older people feel when having cause to complain is a serious manifestation of feeling powerless and vulnerable, and that is a state that is inimical to dignity.

5 Dignity must be actively promoted

For dignity in care to become the universal norm, it is not enough simply to try to reduce or eliminate indignity. It is equally necessary actively to promote dignity. This may mean re-thinking how far, as a society, we wish to invest in preventative care rather than sliding inexorably towards ever-higher eligibility criteria for supportive, dignity-enhancing services. This carries with it all kinds of shifts in attitude to respecting autonomy, promoting meaningful activity and supporting people to make choices and take risks.

6 Dignity is more than the sum of its parts

Dignity is not a formula or a recipe that can be rigidly applied from a manual. In particular, the ‘toolkit’ approach, while useful for improving practice and as a benchmark for assessing performance, cannot fully address the ‘care’ component of dignity in care. Indeed, a formulaic approach, taken outside the context of values and principles, can lead to a situation where all the right boxes are ticked, but still standards fall short of what older people (and other age groups too) want.
Although we argue strongly that dignity is more than the sum of its parts, and is rooted in respect for the person as a whole, it is also true that older people who use care services have every right to expect that each and every aspect of their care should enable them to live with dignity. In this section we look at some aspects of care services – both what they consist of and how they are delivered – to see where there are dignity-related issues of concern. While we have been selective in which aspects of dignity in care to examine here, we believe that this range of issues, encompassing as it does more and less tangible aspects of care, can be taken together to provide good indications of dignity in care as a whole.

It goes without saying that in all of these aspects of care there are many examples of excellent care where dignity is safeguarded and promoted. However, it is legitimate to highlight the areas where dignity is all too often lacking.

Under each heading, we will ask three questions:

- Why is it important to dignity?
- What is the situation now?
- What needs to change?

5 Aspects of dignity
Communication

Why is communication important to dignity?

Communication is at the heart of dignified care. Successive research reports (Dieppe, P. undated) and practice guides (Social Care Institute for Excellence 2006) have reiterated this point. Accounts of the views of older people themselves have made it clear beyond doubt that the right kind of communication can engender a feeling of respect, while poor communication can make the person who is receiving care feel unworthy and uncared for, even if the physical aspects of care are in place. The following quotations reinforce this point.

The extent to which older people are involved in decisions about their care, and listened to by care staff and providers, is an important measure of quality. Communication with care staff is important to older people both for the information that is conveyed and for the quality of the relationship between the person and their paid carer. Older people want to have communication on the tasks to be carried out and issues that are troubling them. They also want to have day-to-day things explained to them, for instance, the change from their shopping or how to fill in a form. Older people often construe the lack of communication from some paid carers as a lack of respect. (Levenson, R. and Joule, N. 2005)

You get the feeling you’re being a nuisance. People may say it’s all in the mind but I think you know by the way you get spoken to, in an abrupt or curt way. (older person quoted) (Help the Aged 2006a)

What is the situation now?

Dignity is all too often undermined by poor communication. This may take many forms and reflect many causes. It is likely that ageism is at the heart of some poor communication, but there are other causes too. Hard-pressed staff are often aware that they are not taking the time to communicate adequately and they would like to have the time to do better. For example, sometimes carers in people’s own homes have 15 minutes or half an hour allocated to perform particular tasks, which leaves virtually no time for any meaningful communication or social interaction with the person being cared for. Pressures on staff time and an unduly task-oriented approach to delivering care play a part in poor communication, although these factors do not excuse it. For example, if health or care staff talk to each other over the head of the person they are caring for, in a way that excludes that person, no possible excuse comes to mind.

Poor communication has been repeatedly implicated when care has gone badly wrong, and it has long been recognised that poor communication is often a last straw that causes people to complain about both health and social care.

There are also repeated indications that one fundamental aspect of dignity is often breached when caring for older people, that is, they are frequently addressed by a first name without their permission (and indeed often making incorrect assumptions about which first name they actually use in everyday life), or an informal term of endearment (‘sweetheart’ or ‘darling’) or by an impersonal age-related term (‘Granny’ or ‘Grandad’). Talking to older people as though they are children is also fairly common.

A recent article in the British Medical Journal (Falconer, M. and O’Neill D. 2007) noted that the terms ‘elderly’, ‘aged’ and ‘old’ were disliked by older people, particularly ‘elderly’. The authors also observed that in biomedical literature, ‘elderly’ is used quite commonly, but in any other context, elderly is a pejorative term. As they wryly observe, who would want to buy an elderly car? Communication about older people can also be damaging to their self-esteem and dignity. Terms such as ‘bed blockers’ (to denote people who are medically fit for discharge but are unable to gain access to suitable support services) and ‘frequent fliers’ (to denote patients who need to use health services frequently) are extremely damaging.
And even more of a gross affront to dignity are the many frankly abusive terms for older people, such as ‘wrinklies’ and ‘crumblies’. Disrespect to older people is also implicit when services distinguish between ‘adults’ and older age groups, as though older people were not properly adults.

What needs to change?
The things that need to change are really rather obvious: take time to communicate; communicate with those being cared for as equals; communicate respectfully with and about older people; take time to communicate properly: do not see communication as separate from care; always ask people how they wish to be addressed, and so on.

However, changing behaviour on this fundamental aspect of dignity will require further efforts to challenge and eliminate ageism. It will also require a level of investment in care that does not force staff to be hasty in their communication. Meanwhile, better training (some of it delivered by older people themselves) and more effective management can make a significant impact on poor communication.

At the most basic level, older people should never be called by a first name without having been asked what they wish to be called – and the answer should be remembered at all times.

Privacy

Why is privacy important to dignity?
Privacy is widely thought to be closely allied to dignity and both older people, their families and carers frequently express concerns about lack of privacy. Privacy extends to having private, personal space, and having opportunities to conduct one’s business without being seen or heard by others. Privacy is particularly important when caring for one’s own personal hygiene and toilet needs, and when being helped to do so. The fundamental importance of privacy is recognised through its protection in Article 8 of the European Convention of Human Rights.

What is the situation now?
The Dignity in Care public survey showed that people still do not have enough privacy when receiving care (Department of Health 2006a). However, the need for privacy is widely recognised, if not respected. The Dignity Challenge includes the specific challenge to respect people’s rights to privacy. Linked to this are a series of privacy-related dignity tests, as follows:

- Do we have quiet areas or rooms that are available and easily accessible to provide privacy?
- Do staff actively promote individual confidentiality, privacy and protection of modesty?
- Do we avoid assuming that we can intrude without permission into someone’s personal space, even if we are the care giver?
- Can people receiving services decide when they want ‘quiet time’ and when they want to interact?

(Social Care Institute for Excellence 2006)

Regrettably, in practice, a lack of privacy can manifest itself in a variety of ways. Both in hospitals and in social care settings, complaints about lack of privacy are relatively common. At their worst, complaints indicate that people are not even properly afforded privacy when they use the toilet. They may also suffer exposure because of gowns that gape, or because of inattention to preserving their modesty and privacy while offering personal care. Reports of older people lying in beds without clothing on the lower part of their bodies in order to make life easier for staff still persist. It is clear that privacy and dignity are closely related and that safeguards for both are lacking.

In hospitals in the UK, privacy is often only possible to a limited degree, particularly where ‘Nightingale wards’ (long wards without
sub-division into small bays) still exist. In those cases, privacy around a patient's bed is maintained only to the extent that curtains are pulled, though curtains do not insulate the patient in terms of sounds or smells penetrating the curtain boundary.

**Mixed-sex wards**

One aspect of privacy that continues to cause enormous concern is mixed-sex wards.

In 1997 the government made a pledge to abolish mixed-sex wards in hospitals and to replace them with single-sex accommodation. Single-sex accommodation is defined by the Department of Health as separate sleeping areas for men and women, segregated bathroom and toilet facilities for men and women and, in those trusts providing mental health services, safe facilities for the mentally ill. This can take a number of forms. NHS trusts may provide single-sex wards, or combinations of single rooms and single-sex bays.

By 2004, it was reported that:

- 98 per cent of NHS trusts provide single-sex accommodation
- 95 per cent of NHS trusts meet additional criteria set for mental health facilities
- 93 per cent of NHS trusts provide separate toilet and washing facilities, with a further 2 per cent planning to meet the standard shortly.

(Department of Health 2004)

The Secretary of State has continued to make claims that the situation is improving, and recently reported to Parliament that 99 per cent of hospital trusts say that they now provide single-sex accommodation in their general wards along with single-sex bathrooms and toilets.

(House of Commons, Hansard 2006)

However, there is a wide discrepancy between official accounts of the mixed-sex ward situation and the views of people who use hospital services. The latest figures from the Healthcare Commission's 2005 survey of patient experience showed that one-fifth of patients (22 per cent) had shared accommodation with the opposite sex at some time during their hospital stay. In London teaching hospitals, the situation was even worse as one in four patients had been in a mixed ward. In some hospitals, in London and beyond, well over half had spent time in a mixed-sex ward.

**What needs to change?**

The need for change is more about practice than policy. Most health and care agencies are fully signed up to ensuring privacy, but a range of factors prevents that from happening. The focus on improvement needs to address those obstacles to good practice. Much of this is about ensuring that person-centred care becomes a reality. For example, in hospitals, good practice would indicate the need to ensure the highest standard of privacy possible for confidential or sensitive conversations. This will include taking people off ward rounds to side rooms and not discussing difficult or distressing subjects at the end of the patient's bed. In social care, it would require taking the time to help people towards their own rooms or to other private space when having sensitive and personal conversations. These changes would require changed attitudes, and also probably a higher level of investment to make the time to deliver private and dignified care.

In the case of mixed-sex wards, what is required at this point is an honest debate on what actually constitutes a mixed-sex ward. Only then can action be geared towards a genuine and comprehensive elimination of this major threat to dignity and privacy.

It is also clear that many people, of all ages, continue to be unconvinced that single-sex accommodation is actually being provided (BBC 2006). Most people do not feel they are in single-sex accommodation if they can see and be seen by patients of the opposite sex. If service users, and particularly older people, defined what mixed-sex and single-sex accommodation looked like to them, we can be
Aspects of dignity

sure that compliance of almost 100 per cent would not be reported by most NHS hospitals. The current situation is a fudge, where the goalposts have moved so that NHS hospitals can report progress to a far greater extent than the actual situation merits.

While the solution may ultimately lie in the replacement of Nightingale wards, it must be borne in mind that for most of the NHS’s history single-sex accommodation was wholly delivered within Nightingale wards. It is most probably extremely high bed occupancy that led to mixed-sex wards, rather than ward layout – though that is not to deny that smaller bays and single rooms would be preferable for most people.

Self-determination and autonomy

Why are self-determination and autonomy important to dignity?

Older people frequently report that they wish to have as much control as possible over their own lives. However, control is easily lost when one is dependent on others for care. People who have not yet reached old age often anticipate the loss of autonomy with dread. For many people, efficient and even kindly care does not support their sense of dignity if it does not enable them to feel that they have some control over their own lives (Levenson, R., Joule, N., Jeyasingham, M. 2005).

What is the situation now?

Although it is one of the stated aims of the Government’s Dignity Challenge (Social Care Institute for Excellence 2006) to enable people to maintain the maximum possible level of independence, choice and control, the reality does not match up to the challenge. Participants in the British focus groups, convened as part of the Dignity and Older Europeans project (Tadd, W. 2004), stated that they had little opportunity to participate in decisions and policies that affected their lives, and when decisions were made there was no named person, just a faceless bureaucracy. They also stated that autonomy and equality were important to their sense of dignity.

Many interesting examples of how self-determination and autonomy are promoted and undermined are found in My Home Life: quality of life in care homes. (Help the Aged 2006b). This report was produced as part of a programme entitled Dignity in Care, and is a collaboration between Help the Aged, the National Care Homes Research and Development Forum, older people and representatives from the care homes sector. It urges a patient-centred rather than process-driven approach, focusing on meaningful activity and shared decision-making.

The Commission for Social Care Inspection has published a report on risk (Commission for Social Care Inspection 2006b). This said that older people told CSCI that they want to stay independent for as long as possible, with practical and emotional assistance when they need it. CSCI recognises that meeting their choices and aspirations could sometimes entail some degree of risk. It observes that older people are well placed to make these choices since, by virtue of living longer, they have considerable experience of making judgements about risk.

People also told CSCI they want independence and choice and, importantly, they want to determine how services are delivered. Again, reality falls short of ambition. There are multiple sources of evidence that older people do not feel in control of how their services are delivered. Unhappy stories abound about people who receive care services being put to bed at an early hour for the convenience of the carer. All too often, older people lack the power to challenge care providers who take a rigid approach to how the hours of managed care are allocated.

As people grow older and particularly as they become users of care services, they are often discouraged from making their own decisions about acceptable levels of risk. Interestingly, one study found that older people living in institutions perceived themselves to have greater autonomy in decision-making than older
people receiving domiciliary care. Indeed, living at home did not mean that one's autonomy would be supported (Boyle, G. 2004).

Risk-taking is a vital part of autonomy, and the right to take risks is closely bound up with dignity, particularly for older people who suffer from a kindly but misplaced paternalism. The right to take risks is often sacrificed under the banner of ‘health and safety’. Of course health and safety are enormously important, but the more obvious health and safety considerations have to be balanced against subtler ones. Rules and regulations that sometimes prevent older people making their own tea and toast on the ward or in a care home may tick the health and safety box, but at the expense of enabling them to preserve dignity and control, which should also be seen as elements of safe and high-quality care.

One of the issues that is seldom discussed is the balance of risk between service users and staff who deliver care. To give one example, the use of hoists is often determined by the possible risks to staff of manually lifting people. However, older people frequently say that being placed in hoists severely undermines their sense of control and dignity. The perspectives of both the carer and the person being cared for are entirely understandable and we have to face up to there being a degree of conflict of interest between them; conflict that can only be resolved fairly by balancing both legitimate interests. However, the reality is that currently the right to autonomy and self-determination of the cared-for person is rarely, if ever, recognised at all, despite the fact that it is part of private life protected by Article 3 of the Human Rights Convention. (See also section on human rights in Appendix.)

**The role of Direct Payments in promoting autonomy and control**

In recent years there has been a growing interest in Direct Payments as a means to give people a greater control over their care services. Direct Payments are for self-directed community care and involve service users purchasing and managing for themselves some, or all, of the care they have been assessed as needing. Direct Payments were introduced in 1997 by the Community Care (Direct Payments) Act 1996, allowing local authorities to make Direct Payments to 18–65-year-olds. In England this power was extended to include older people in 2000. The Act has now been replaced, the power has become a duty in many circumstances and recipients now include older and younger people, parents of disabled children and, with the exception of Scotland, carers (for care services to meet their own needs).

Research conducted for the Joseph Rowntree Foundation between January 2002 and June 2003 (Clark, H., Gough, H. and Macfarlane, A. 2004) examined how Direct Payments work for older people in three different local authority areas. The research found that older people receiving Direct Payments reported feeling happier, more motivated and having an improved quality of life. There was a positive impact upon their social, emotional and physical health. However, the research report also noted that support services were crucial in enabling older people to use Direct Payments.

**What needs to change?**

Taking the Direct Payments issue first, much more could be done to support older people to make use of Direct Payments. In so far as this increases autonomy and control, it may contribute to dignity. However, the impact of this should not be overstated, as the amount of payment available and the supply of staff who are trained and competent to deliver care with dignity fall short of what would be required to maximise dignity in care.
Aspects of dignity

In other, broader contexts, both for older people living in their own homes and for older people in hospital, nursing home or residential care, so much more could be done to promote autonomy. Repeated encouragement of person-centred care has failed to alter fundamentally the power relationships that define the delivery of care. A greater use of advocates and independent advisers would help older people to assert their rights. As Counsel and Care notes, supporting and signposting to independent advice and advocacy organisations is key (Asato, J. 2006).

On the question of risk, changed attitudes will require a major shift on the part of health and social care agencies and their staff, but also on the part of service users and carers. Staff are unlikely to be comfortable with supporting their clients to take risks if they are at the same time worried that they will be personally blamed if things go wrong. However, much could be done by care services to enable older people to have what CSCI refers to as ‘an anticipatory voice’ – frankly discussing and planning to assess risks and make their preferences known (Commission for Social Care Inspection 2006b). Training for staff to enable them to facilitate these choices is very necessary.

CSCI also points out that councillors, as local community leaders and members of overview and scrutiny committees, are well placed to promote wider public awareness of people’s rights, as well as to challenge wherever older people are not afforded the dignity and respect they have a right to expect. They also point out that ‘commissioners, providers and regulators in social care need to play their part in promoting this cultural shift, but the challenge extends to policy makers and those responsible for delivering better public services across central and local government – and to local communities that are well placed to promote the rights and choices of all older citizens’ (Commission for Social Care Inspection 2006b).

A human rights-based approach is central to understanding and implementing social policy to promote autonomy and self-determination, because such an approach is premised on the concept of proportionality and of balancing competing individual rights and wider public interest factors. Finally, a wide public debate, informed by human rights principles, needs to take place to develop a consensus on how to balance risk and safety and risk and autonomy, from the perspectives of service users, carers and all of us who may one day be facing major dilemmas on these issues.

Food and nutrition

Why is food important to dignity?

Food is essential to maintaining life and health, but it is also much more than that. For most people, eating is one of life’s pleasures, and it is closely bound up with social life. Having some choice of what to eat, when to eat it and whether to eat alone or with other people are all things that we may take for granted and that may form part of our sense of being in control and living a dignified life. While many older people cook for themselves or eat meals that are prepared for them by family, friends or carers, those who are frail or ill may be unable to do so. In particular, older people who are in hospital and those who are cared for in residential or nursing homes may be highly dependent on others for all aspects of their nutrition, from selecting and preparing meals to helping them to eat.

What is the situation now?

For this most basic of needs, the current situation is still bleak. It is surprising, but true, that when older people are at their most vulnerable, the health and care services on which they depend do not always guarantee adequate nutrition. Nor do they reliably promote dignity through, for example, enabling older people to choose their food or take pleasure in eating it.

These points are often expressed by older people and their organisations, but it is also recognised at the highest levels of government that a very unhappy situation still exists. In
January 2007, Ivan Lewis MP, the Parliamentary Under-Secretary of State for Care Services, addressed a meeting of more than 100 carers in Birmingham, and said:

A single scoop of mashed potato, lonely in the middle of the plate. It’s not an appetising meal. Yet for some elderly patients in hospital, this masquerades as lunch every day. Some older people in care homes and hospital wards are still being served their dinners with plastic cutlery even though they have suffered a paralysing stroke, making it impossible for them to eat properly. Some have a tray placed on the end of the bed, tantalising with hot food. It may be just an inch out of reach but it might as well be a mile. To a bedridden pensioner, it must seem like torture.

Mr Lewis added:

We wouldn’t put up with this happening to our children, so why should we find it acceptable for our older people? (Daily Telegraph 2007).

These uncompromising words reinforced the problems articulated by those who responded to the Department of Health’s online public survey on dignity in care, the results of which were published in October 2006 (Department of Health 2006a). The survey was set up to hear directly from the public about their own experiences of being treated with dignity by care services, or about care they had seen being provided to others. Four hundred people took part, of whom approximately half were professional staff working in health or social-care settings. Respondents to the survey pointed out that there is not enough assistance available to service users to eat meals. Equally important, they were concerned that mealtimes were seen as a procedure to be got over quickly, rather than a social event.

Also in 2006, Age Concern England published a shocking report on nutrition for older patients in hospitals, as part of its campaign Hungry to be Heard (Age Concern England 2006a). The charity reported survey findings\(^1\) that nine out of ten nurses do not always have time to help patients who need assistance with eating, despite shocking levels of malnutrition in older patients.

Drawing on recent European figures, Age Concern England reported that six out of ten older patients are at risk of becoming malnourished or their situation getting worse while in hospital. The figures are worse for those who are older; as patients over 80 admitted to hospital have a five times higher prevalence of malnutrition than those under the age of 50 (European Nutrition for Health Alliance 2005).

Figures from other sources referenced in the European report, referred to above, have indicated that the prevalence of malnutrition in nursing homes varies between 60 per cent and 100 per cent.

The report Hungry to be Heard (Age Concern England 2006a) points out that in addition to the obvious consequences for individuals who may become malnourished in hospital, it is also a costly mistake for the health service to make, since malnourished patients stay in hospital for longer; are three times as likely to develop complications during surgery and have a higher mortality rate. They report that malnutrition costs the health service in the UK in excess of £7.3 billion per year – much more than obesity.

Sometimes, older people develop problems in swallowing, perhaps after a stroke or in the advanced stages of dementia. There is a wealth of information – mostly in the American medical journals – about tube-feeding patients with advanced dementia that contends that tube-feeding makes no difference to the length of life and has no beneficial impact on a range of clinical indicators, such as pressure sores or infections. Nor does it make the person more comfortable. But it does carry significant risks.

There are also indications that tube-feeding may be considered for a variety of reasons other than maintaining appropriate nutrition. Such reasons may include a strange view of the

\(^1\) ICM polling conducted for Age Concern, August 2006
relative risks associated with tube-feeding and feeding by hand. We also know that in the United States tube-feeding is associated with a variety of factors – such as age, gender and marital status – and not only with clinical need, although it is not clear whether these findings apply to the UK (Mitchell, S. et al. 2003). In the USA, there are also reported financial incentives for nursing homes to tube-feed residents (Gillick, M. 2006). The situation is not exactly the same in the UK, but it is possible that staffing levels and the time available to staff to assist with feeding people with swallowing difficulties may be factors in deciding that tube-feeding is indicated, as may be issues relating to multi-disciplinary work and the assessment of risk (Levenson, R. 2004).

**What needs to change?**

There is already a wealth of good-practice guidelines to draw on, and a number of initiatives to ensure that older people are given support so that they can eat properly and can derive as much satisfaction as possible from mealtimes. Some of the measures are simple and inexpensive, such as the provision of red trays to people in hospital who need help to eat their meals (Department of Health 2006e; Age Concern England 2006a). The fact that there are such glaring failures in applying such inexpensive and simple best practice across the board is a scandalous failure.

As SCIE’s Practice Guide to Dignity in Care states:

*Nutritional screening should be a key part of care planning: malnutrition affects over 10 per cent of older people, and is costly in economic terms as well as for individual health. Mealtimes should also be seen for their social opportunities: initiatives include local lunch clubs, and many hospitals have introduced ‘protected mealtimes’. While socialising should be encouraged, privacy and discreet support is needed to avoid embarrassment or loss of dignity for those who have difficulties with eating.*

(Social Care Institute for Excellence 2006)

The report from Age Concern referred to above spells out the steps that hospitals must implement to eradicate avoidable malnutrition and ensure that older patients get the food they need and help with eating.

(1) **Hospital staff must listen to older people, their relatives and carers**

(2) **All ward staff must become ‘food-aware’**

(3) **Hospital staff must follow their own professional codes and guidance from other bodies**

(4) **Older people must be assessed for the signs or danger of malnourishment on admission and at regular intervals during their stay**

(5) **‘Protected mealtimes’ should be introduced**

(6) **Implement a ‘red tray system’ and ensure that it works in practice**

(7) **Volunteers should be used where appropriate.**

The report also makes recommendations to the NHS, the Healthcare Commission and the Department of Health. There is no shortage of evidence on how to ensure that good nutrition and happy mealtimes, as essential aspects of dignity, are put in place. What is needed now is the will to do so.

**Pain and symptom control**

**Why is pain and symptom control important to dignity?**

It is challenging to maintain a dignified existence in the face of pain and extreme discomfort, and particularly if help to deal with pain and other symptoms is not delivered as well as it might be. Making sure that people are not left in pain was considered to be a key aspect of dignity by respondents to the Department of Health survey in 2006 (Department of Health 2006a). Adequate pain relief at the end of life has also been identified as a component of a dignified death (Birrell, J. et al. 2006).
**What is the situation now?**

Unfortunately, recent evidence confirms that cared-for frail and older people are often left in pain unnecessarily. The extent of this is revealed in a new report commissioned by the Patients Association and conducted by the Picker Institute (Cairncross, L., Magee, H. and Askham, J. 2007) which looked at the experience of nursing-home residents in relation to pain control.

Eighty-five per cent of those interviewed for the study said a doctor or nurse had never talked to them about how the often constant pain they suffer could be treated, while 57 per cent had never been asked about their pain by nursing-home staff responsible for their day-to-day care. Nearly two in five residents had experienced constant pain and 8 per cent described their pain as excruciating. Despite this, many of those in such pain are not able to initiate or not comfortable about initiating conversations about their pain, making the role of the doctor or nursing-home staff all the more important in prompting discussions and assessments.

The findings support earlier research conducted by the Patients Association in 2006 on the carer’s perspective of looking after older people in pain, in which 39 per cent of non-professional carers reported that healthcare professionals never or only occasionally reviewed their patients’ pain level.

**What needs to change?**

Essentially, a more proactive approach is needed to ensure that the dignity of older people is not threatened by unnecessary pain or discomfort. This is all the more necessary because older people are reputed to be unwilling to complain and sometimes worry about being seen as a nuisance.

The British Geriatrics Society calls for locally agreed protocols to optimise management of pain control, nutrition, pressure sore risk, fluid balance, delirium, falls, continence, depression, infection control and palliative care (British Geriatrics Society 2003).
Aspects of dignity

Personal hygiene, bathing and using the toilet in hospitals and care homes

Why are hygiene, bathing and using the toilet important to dignity?

In addition to the obvious links between health and hygiene, most people see the maintenance of cleanliness and a good appearance as closely bound up with their sense of dignity and self-respect. Maintaining personal hygiene is commonly cited by older people as essential to dignity. Privacy when washing, bathing and using the toilet are extremely important. Most people would not feel that using a commode behind a curtain provides privacy: they feel embarrassed for themselves if they have to do so, and embarrassed also when others have to do so.

What is the situation now?

The Department of Health survey referred to above (Department of Health 2006a) confirmed that concerns about using the toilet were among the main issues that respondents mentioned. In particular, they said that there is insufficient access to lavatory and bathroom facilities, and that help is not always available when needed.

The overall condition of hospital bathrooms and showers remains unsatisfactory. Too many hospital bathrooms are austere, cold, smelly and poorly maintained. Toilet and bathroom facilities in hospitals remain poor. There have been some improvements, particularly in the provision of bath hoists, adapted taps, alarm-call systems, shower seats and wheelchair access to bathrooms. Nevertheless, many basic problems remain, such as absent locks and signs, inadequate heating, poor standards of privacy, insufficient bath aids, wet floors, and the inappropriate use of bathrooms as store rooms (Monro, A. and Mulley, G.P. 2004).

Personal experiences of older people and their carers tell a sad story of dignity being compromised by poor practice when older people need to use the toilet in hospital or care services. As they observe, and as is confirmed by campaigns such as ‘Behind Closed Doors’ (British Geriatrics Society 2006a), which is endorsed by the British Geriatrics Society, Help the Aged, Research into Ageing, Age Concern England, the Continence Foundation, InContact, Carers UK and the Department of Geriatric Medicine, Cardiff University, dignity and human rights are undermined by failure to provide good care in relation to an extremely basic need.

It is still not unusual for patients in hospital wards to have to use commodes, rather than staff taking them to the toilet when needed. It is by no means universal for patients in hospitals to be offered hand-washing facilities after using a bedpan or bedside commode. Certainly, anyone who has regularly visited older people in hospital or care homes will be aware that people still have cause for complaint about delays in call bells being answered, resulting in the person being unable to use the toilet when it is needed. Older people report subtle or not-so-subtle pressure to use incontinence pads, or even to soil their bedding, rather than make repeated or urgent requests to use the toilet. This is further borne out by cases reported to the Help the Aged telephone advice service, SeniorLine. It is a gross interference with human rights, both Article 3 (protection from inhuman and degrading treatment) and Article 8 (respect for private life).

In care homes, it is still often the case that taking people to the toilet is timetabled into the day: for example, a mass and rather public attendance at the toilet just before meals and bedtime. This ritual is often conducted without any apparent regard to the person’s dignity. Also, there are still reports of access to bathing being restricted to certain days. While this may meet ‘tick-box’ standards of regular bathing, it does little to preserve or promote the dignity of the individual who simply wishes to have some control in when and how he or she is helped to bathe.
Matters of hygiene and personal appearance are not universally approached in ways that maintain dignity. Clearly, many staff do understand the importance of personal appearance, and it is not unusual for staff to take time to help frail residents in care homes to maintain their personal appearance: for example, by styling their hair or by applying nail polish. However, the older person in care with her newly polished nails may be sitting in a wet or soiled pad as someone has decided to prioritise nail polishing over taking her to use the toilet when she needs it.

What needs to change?

‘Behind Closed Doors’ sets out best practice that upholds human dignity, and describes poor practice which violates human rights and denies dignity. It also sets out comprehensive standards that need to be implemented with great urgency. These are quoted below:

**Safety**
People who are unable to use a toilet alone safely should normally be offered use of a toilet with appropriate safety equipment in place and with supervision if required.

**Choice**
People’s choice is paramount. Their views should be sought and respected.

**Privacy**
Privacy and dignity must be preserved. People who are bed-bound require special attention.

**Cleanliness**
All toilets, commodes and bed pans must be clean.

**Hygiene**
All people in all settings must be enabled to leave the toilet with a clean bottom and washed hands.

**Respectful language**
Discussions with people must be respectful and courteous, especially with regard to episodes of incontinence.

**Environmental audit**
All organisations should encourage a lay person to undertake an environmental audit to assess the toilet facilities.

**Personal care and help at home**

**Why is personal care important to dignity?**

There has been a long-standing and increasing emphasis on care in the community for both health and social-care needs. This is in line with what older people want. But dignity in one’s own home can be a fragile commodity if sufficient help is not available to attend to personal care needs at home and to maintain a clean environment.
What is the situation now?

With regard to household cleaning, for some years local authorities have taken an ever-decreasing role in enabling older people to maintain a clean home, and most people who need help with cleaning have to make their own arrangements.

A review of what older people say about care services, submitted to the King’s Fund Care Services Inquiry in 2004 (Levenson, R. and Joule, N. 2005), referred to older people feeling strongly about these needs. The report cited evidence that older people require care packages that enable support for low-level needs, such as assistance with cleaning and shopping, before they become more dependent and have high-care needs. More recent information in The Observer reports some worrying examples of rationing and cutbacks in social care, including personal care and home care (The Observer 2007).

The same pattern is true for many aspects of personal care. Under Fair Access to Care Services (Department of Health 2002), councils assess the risks to independence if needs are not met in four categories: critical, substantial, moderate and low. Councils decide which categories they can provide care for within their budgets, and will provide information, but not services, to those who fall outside these categories.

Recent evidence suggests continuing concern about the number of people who do not fall within eligibility criteria for any care at home. The Commission for Social Care Inspection recently pointed out that thresholds for accessing services are high. For two-thirds of councils, the threshold for care-managed services was set at ‘substantial’ in 2005–6 and a number of councils are expecting to raise their eligibility thresholds in 2006–7 (Commission for Social Care Inspection 2006a). Indeed, there have been press reports that some councils are moving towards providing care packages only to those whose care needs are assessed as ‘critical’. This is likely to pose a further threat to the dignity of those older people who need a fairly low level of help for personal care or care of their homes.

What needs to change?

A completely different focus is required if promoting dignity is to be seen as important. The change needs to embrace a recognition that the person with few needs or low-level needs may actually require help just as much as the person with substantial or critical levels of need. The assumption that this would be very costly should be tested, as it may well be the case that a small amount of the help that people want, when they want it, would reduce the need for more costly packages of care later on.

A change in focus would also constitute a move away from a biomedical approach to care. For example, an older person who is depressed at not being able to keep a tidy garden may benefit more from help to maintain the garden than from a prescription for anti-depressants. As noted above, Direct Payments help to some extent in enabling older people to choose what kind of care they need most. However, assessments of need are not normally generous enough to allow a great deal of flexibility, and dignity suffers accordingly.

Death with dignity

Why is it important to die with dignity?

Many people are vulnerable to affronts to their dignity at the end of life, and some people become less able to assert their own rights to dignified care. A loss of dignity at the end of life is feared by many people. Concerns about dignity at the end of life extend to dying at home, in residential and nursing homes and in hospitals. For some, a lack of support to die in their own home is, in itself, a factor that undermines their dignity. The views expressed in a report by the Health and Older People (HOPe) group in 2000 (HOPe group 2000) still hold good: respect and understanding for those who are dying should be integral to all health and care settings.
The Challenge of Dignity in Care

What is the situation now?
An overview of mortality in the UK was undertaken by Jane Seymour and her colleagues at the University of Sheffield for Help the Aged (Seymour, J. et al. 2005). It looked at the end-of-life experiences of older people, including those suffering from heart failure and dementia. It surveyed the types of care provided and the environments in which death occurs. It concluded that if a ‘good death’ means that a person has privacy, dignity, good-quality care in comfortable surroundings, adequate pain relief and respect for personal preferences, many people cannot expect to have one.

Older people are less likely than younger people to have access to palliative care, particularly if they have a diagnosis other than cancer. The extension of palliative care to older people is progressing slowly. Older people who die on an acute ward in hospital all too often die in an environment that is incompatible with the kind of dignity that is needed at the end of life.

We also know that at present about 20 per cent of the population die in care homes, making these a significant place for care at the end of life for older people (Froggatt, K. 2004). The standard of end-of-life care in care homes is variable and often people are inappropriately admitted to hospital at the very end of their lives.

What needs to change?
Seymour’s report (Seymour, J. et al. 2005) makes a number of recommendations that remain relevant. These cover practice and education, policy and research.

It is also noteworthy that basic policy and good practice are already set out in nationally agreed documents, and the real challenge is in implementation. For example, Programme 2: ‘Dignity at the end of life’ in the Department of Health’s New Ambition for Old Age (Department of Health 2006h) has two aims:

1. to adapt and spread the three best-practice models, as appropriate, for end-of-life care of older people living at home (Gold Standards Framework (GSF), Preferred Priorities for Care (PPC), Liverpool Care Pathway (LCP) or in hospital (LCP, PPC), in line with other adult needs;
2. to facilitate best practice in commissioning, delivery and education in end-of-life care in care homes.

If these aims were realised, dignity at the end of life for older people would be much more assured. The GSF is particularly important. The GSF is one of the three best-practice tools which have been developed through the Department of Health’s End-of-life Care Programme. Together with the Liverpool Care Pathway for the Dying Patient, and the Preferred Priorities for Care tool, the GSF seeks to identify and address people’s needs and preferences at the end of life.

A modified version of the GSF has been developed for care homes (GSFCH) to improve the quality of end-of-life care in care homes, improve collaborative working with primary health care teams, and reduce the numbers of patients transferred from care homes to hospital at the very end of life. The GSFCH is based on the same GSF principles of ‘identify, assess and plan care’, using the same key tasks, templates and assessment tools.

Social inclusion

Why is it important to dignity?
The subject of social exclusion is too vast to consider in detail here. However, numerous reports have highlighted that older people are often socially excluded. A 2006 report to the Office of the Deputy Prime Minister (Barnes, M. et al. 2006) argued that social exclusion was multi-dimensional. The authors described seven dimensions of social exclusion:

- social relationships (contact with family and friends);
- cultural and leisure issues (for example, going to the cinema or theatre);
- civic activities (for example, membership of a local interest group, voluntary work, voting);
basic services (for example, health services, shops);
neighbourhood (for example, safety and friendliness of local people);
financial products (for example, bank account, pension); and
material goods (for example, consumer durables, heating).

While they found that about 50 per cent of older people were not included in any of these dimensions, 29 per cent were included on one dimension, 13 per cent in two or more dimensions and 7 per cent in three or more dimensions. Being over 80 years of age was particularly linked to experiencing multiple exclusion.

While not all of these dimensions are central to dignity in care, we argue that they are indirectly relevant since dignity in care cannot be isolated completely from the dignity of the whole person. In so far as care services fail to maximise and promote social inclusion, we argue that they compromise dignity. This is supported by the wide scope of Article 8 rights protected under the Human Rights Convention, recognising that the right to private life must extend to social relations and to participation in the wider life in the community.

What is the current situation?

In many areas of life, older people experience social exclusion, rejection and ageism.

A recent report from the Research on Age Discrimination Project (RoAD) to Help the Aged (Blytheway, B. et al. 2007) illustrated this with statistics and vignettes relating to many aspects of life for older people. For example, as well as the assertion that 73 per cent of people agree that older people face discrimination on grounds of age in their everyday lives, the report gives these alarming figures:

Public places

- 68 per cent of people agree that there is a shortage of benches and seating in public places.
- One-third of older people have difficulty participating in public consultations.

The marketplace

- 53 per cent of people agree that businesses and retailers have little interest in older people’s consumer needs.
- 95 per cent of annual travel insurance policies impose an upper age limit.

Appearance and fashion

- 70 per cent of people agree that older people who try to look or dress young are seen as a joke.
- 45 per cent agree that films and advertisements portray older people as figures of fun.

Health and the health service

- 40 per cent of people believe that health professionals see older people as a nuisance.

Family life and decision-taking

- 58 per cent of people agree that once you reach old age, families assume you cannot make decisions for yourself.
- 68 per cent agree that once you reach very old age, people tend to treat you as a child.

Care and vulnerability

- 76 per cent of people think that care-home residents tend to be forgotten by society.
- 59 per cent of people with someone close to them who lives in residential care feel that care homes often neglect their individual wishes.

Fear and isolation

- 65 per cent of people agree that local communities neglect older people who have become socially isolated.

These are depressing figures, and many of the stories that illustrate the stark statistics make it plain that social exclusion and a loss of dignity are closely intertwined. Another report from Help the Aged tells a similar story (Help the
A woman aged 71 is quoted as saying:

*Old people are pushed aside – the attitude is, you’ve had your time now, it’s time you went.*

To illustrate the problem of social exclusion in one specific area, we look at how older people in receipt of means-tested residential care services are socially excluded, resulting in a loss of dignity. A report from Age Concern England focuses on this issue (Age Concern England 2006b).

As things stand, almost 260,000 people need financial support from the state to pay their care-home fees. This represents well over half of the total number of people living in care homes, and the vast majority of these people are 65 years old or over (most are aged over 85). As they are required to contribute to the costs of their care, they surrender most of their only source of income – their pensions – to pay towards the care-home fees. They are entitled to retain only a Personal Expenses Allowance (PEA) of £19.60 per week to cover the cost of all the personal items not covered by their care-home fees. Department of Health guidance (Department of Health 1992) states that the PEA ‘is intended to enable residents to have money to spend as they wish: for example, on stationery, personal toiletries, treats and small presents’.

In fact, this amount of money would probably not even cover those items, and the reality is that many older people often have to spend their allowance on services such as chiropody and physiotherapy, where long waiting lists or restricted eligibility criteria leave them little alternative.

Age Concern, Help the Aged and many other organisations believe that the PEA given to older people in care homes is symbolic of the way that older people are treated in society and undermines independence, choice and dignity.

There is also a growing concern about those who fund their own care. A policy discussion paper from Counsel and Care (Asato, J. 2006) calls for: support for those who use private assets to fund their care, along with a clearer settlement which sets out what costs individuals will be expected to meet with their capital and savings. There needs to be a national debate, similar to the recent pensions debate, in which the challenges of funding care in the future are honestly discussed with the public and a settlement reached on the best way forward.

**What needs to change?**

In so far as social exclusion is related to widespread ageism in society, there is no quick fix. Debate and action to improve the status of older people in all aspects of society continue to be necessary. However, many of the manifestations of how older people are undervalued and treated without due dignity can be tackled, partly by introducing legislation on age discrimination and by making fuller use of human rights legislation, not only to challenge practice which violates rights, but also to promote a positive culture of respect for rights. This would significantly help to bring about the much-needed changes in attitudes and behaviours. Older people themselves are well placed to take a leading role in working for an end to ageism, discrimination and social exclusion, but they should by no means be held solely responsible for making these changes come about.

The low level of the Personal Expenses Allowance is a matter for politicians. For a modest cost, the threat to dignity posed by some of Britain’s most vulnerable older people having insufficient means for personal needs and for some social life could be altered with a flick of the pen, and it should be.

In the context of care services, service providers could do a great deal more to ensure that the workforce at all levels is educated to uphold human rights, challenge ageism and promote social inclusion. Commissioners of services could flex their muscles more in order to specify how this needs to take place in order to include appropriate content. Managers of
care services could also lead by example, and take a zero-tolerance approach to behaviours that exclude older people. Regulators could also be more proactive by insisting that regulated services comply with fundamental human rights and by promoting a positive human rights-based culture in their approach to measuring standards.
6 Safeguarding and promoting dignity

In the previous section many areas of concern were identified, together with indications of how dignity can be maintained or improved in specific situations. However, as we have illustrated throughout this report, tinkering with (or even radically altering) current practice is unlikely to lead to sustained improvements in dignity in care. In addition to adhering to the principles outlined in Section 4 and acting on the areas that need to change in Section 5, there are some other issues that need attention if dignity in care is to be safeguarded and promoted. These are outlined only briefly here but each could merit a report of its own:

1. Respect and recognition for staff and others who care for older people
2. A new approach to education for staff working with older people
3. Making better use of complaints
4. Advocacy
5. A new approach to involving older people.

1 Respect and recognition for staff and others who care for older people

The relatively low status of older people in our society is reflected in the status of those who care for them. Even within the medical and nursing professions, the care of older people is seldom held in quite such high esteem as other specialisms. In social care, it is often those who deliver hands-on care who are respected and rewarded least, although the contribution they make to all aspects of well-being, including dignity, is enormous. While undervaluing staff and family carers (financially and otherwise) is neither an explanation nor an excuse for failing to ensure dignity in care, it is not possible to have an effective campaign for dignity in care without also campaigning for dignity for carers – both those who are paid to care and those who do it out of love or a sense of duty.

2 A new approach to education for staff working with older people

There is evidence that training opportunities for frontline care workers are inequitable and that available training does not always contribute to promoting person-centred care as fully as it might. It is also suggested that frontline care workers feel there is a lack of recognition of the skills that they gain through experience and that this may be an increasing problem as the focus of training is shifting towards the attainment of qualifications (Innes, A., Macpherson, S. and McCabe, L. 2006). Equally, while care workers are usually very keen to improve their skills and the quality of service, not all workers are interested in obtaining qualifications (McFarlane, L. and McLean, J. 2003) – despite the targets in place for the majority of the care workforce to hold National Vocational Qualifications.

It is time for a fresh look at the training needs of care staff who work with older people and to review how to educate staff so that they can actively promote dignity and person-centred care. It is telling that the British Institute of Human Rights reports a positive and excited response by frontline staff to human rights training.

In reviewing training, it would be timely to consider how older people themselves can help to plan and deliver training programmes, thereby ensuring greater relevance, but also challenging ageist assumptions about older people only being receivers of services, rather than active partners in care.
3 Making better use of complaints

Even allowing for the fact that most older people who have cause to complain do not do so, when they do there is a perception that not enough is done about the complaint (Department of Health 2006a). There is, nevertheless, a great deal of material available from the investigations of complaints, in both health and social care. Reports of these investigations often yield valuable material about dignity in care, and particularly about the circumstances in which dignity is not achieved. Yet the material from all available sources (the Healthcare Commission, the health services ombudsman, CSCI etc.) is not usually put together to see whether there are recurrent themes or indicators of either good or poor practice. Nor is information about issues that are highlighted by ‘whistle-blowing’ staff routinely analysed across the range of health and care organisations in the whole country. Given an increasing plurality of providers, a national overview of how dignity is maintained or breached is increasingly necessary. Complaints data are one source of this material.

Older people should also be encouraged to complain about any care services that do not provide dignified care. There should be explicit reports of the learning that has taken place in each organisation from complaints about breaches of dignity. These lessons should be drawn from complaints at all levels, including those which are resolved at an early stage within the organisation that is complained about.

4 Advocacy

The use of advocates has been mentioned in this report as being a route to helping older people to make their voices heard. This is particularly important for the most frail among older people, for those with communication difficulties and for those who have a high level of dependency on others. Yet the availability of advocacy remains patchy and ‘further research and work could be done to develop advocacy standards which are particularly relevant to older people, care home application and dementia advocacy’ (OPAAL 2006).

There should be national standards for the provision of advocates for older people, as advocates can make a significant contribution to safeguarding dignity in the care of older people. Advocates also need the support of independent specialist legal advice in the complex areas of social and healthcare legal issues and human rights. Unfortunately, such specialist expertise is rarely available in practice and current proposals to reform the Legal Aid system will make it more difficult for specialists in this field to survive.

5 A new approach to involving older people

For all the rhetoric about patient and public involvement (PPI), too little is done to enable older people to participate in shaping and monitoring services in ways that suit them. This is particularly true for less active older people. Constant (and continuing) upheavals to PPI structures have not been helpful. This is too big a subject for this report, but it must be noted that unless older people are enabled and supported to engage more fully with the services they rely on, dignity in care will be so much harder to achieve and sustain.
7 Developing metrics for dignity in care

The story so far

According to the Healthcare Commission’s website, the term ‘metrics’ refers to:

*measures of performance, such as indicators, targets or benchmarks, which are used to assess and monitor the quality of care that patients receive in health services.*

Since 2004, the Healthcare Commission has been working on its Better Metrics project (Healthcare Commission 2006), which aims to improve the way in which performance of health services is measured, by:

- developing metrics that are more relevant to the work of doctors, nurses and others who provide care to patients;
- identifying metrics that are already being used successfully by organisations to monitor and improve performance; and
- sharing metrics with the Connecting for Health programme, as part of the process of developing electronic patient records, to improve routine monitoring of key clinical areas.

Variously described as ‘a pragmatic programme’ and ‘work in progress’, Better Metrics sets out a number of measures that apply to older people, among others, as well as including a specific section on metrics relating to older people. The themes and objectives in this section, together with a description of the metrics for each, is as follows (with the numbering as in Better Metrics):

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2 In this context, however, we use the term ‘metrics’ to apply to such measures in the wider context of health and social care, where the term ‘service user’ would be more appropriate and inclusive than the term ‘patient’.
10.01 **Theme:** Better assessment and care  
**Objective:** To promote unified multi-agency assessment  
**Description of metric:** Proportion of people aged 75 and above who have had a contact and overview assessment in the last year, or an update, and have received a personal care plan.

10.02 **Theme:** Better assessment and care  
**Objective:** To improve support for carers  
**Description of metric:** Population percentage of assessed older people whose carers have received a carers’ assessment.

10.03 **Theme:** Better assessment and care  
**Objective:** To avoid overlooking remediable medical, mental health and social issues prior to admission to long-term care  
**Description of metric:** Proportion of older people admitted to long-term care (residential/nursing home/intensive home care) who have received comprehensive level assessment prior to admission.

10.04 **Theme:** Better assessment and care  
**Objective:** (1) To reduce falls (2) To improve the appropriateness of medication  
**Description of metric:** Population percentage of older people on four or more drugs who have had a medicines review in one year.

10.05 **Theme:** Better assessment and care  
**Objective:** To reduce the frequency of falls in older people  
**Description of metric:** Proportion of older people (75+) with more than one fall in the last 12 months on risk register and reviewed by falls service.

10.06 **Theme:** Better assessment and care  
**Objective:** To reduce the frequency of falls in older people, particularly those with non-cancer terminal conditions  
**Description of metric:** Proportion of deceased older people with evidence of good end-of-life care prior to death (one of Preferred Place of Care, Liverpool Care Pathway, Gold Standards care or equivalent)

10.07 **Theme:** Population health and well-being  
**Objective:** To promote the ability to live independently  
**Description of metric:** Population level of independence in activities of everyday living by age bands 65 to 74, 75 to 84, 85 plus.

10.08 **Theme:** Population health and well-being  
**Objective:** To reduce excess winter death rates  
**Description of metric:** Excess winter death rates by local geographic clusters.

As can be seen from the above, these metrics are all useful to assess aspects of (mostly medical) care, and some of them are relevant to a wider notion of dignity in care. However, taken together — and even including other metrics set out elsewhere — these metrics fall short of what would be required in order to assess whether dignity in care was being achieved. Nor would they be adequate as a tool to assess the rate of progress towards dignity in care for older people, and to be fair, they are not intended to address these issues comprehensively.

During 2007, the Standards and Quality Analytical Team at the Department of Health has been working on a Dignity in Care Framework. This work continues during the first half of the year and is intended to lead to the production of indicators and performance measures at three levels:
Developing metrics for dignity in care

Level 1: High-level performance indicators for the Department of Health’s performance assessment work.

Level 2: A larger set of metrics for inspection and regulation, i.e., adoption by the Healthcare Commission and Commission for Social Care Inspection.

Level 3: A long list which local organisations would find useful in their self-reporting and benchmarking functions.

For each indicator, information will be provided on the source of material, which will include a wide variety of sources, including the Patient Experience Survey, National Minimum Standards for domiciliary care agencies, Essence of Care Benchmarking Reviews etc.

A new approach: meaningful metrics for dignity in care

Formal Department of Health metrics are becoming more sophisticated in what they aim to do, but by their nature they are unlikely to be able to address some of the nuances of dignity in care which are so important to older people. One important issue is that people who use services are particularly interested in outcomes (how it was for them). By contrast, many ‘official’ metrics remain very process-oriented. To put this most simply, an undue focus on process can lead, for example, to health and care organisations producing evidence of the use of ‘training packages, information and communication channels’ as required by Essence of Care benchmarking, but without there necessarily being any complementary evidence from older people to indicate whether such materials have made a discernible difference. At its worst, processes can be in place but outcomes, in terms of dignity as perceived by a service user, can remain poor.

One of the challenges of coming up with metrics that are meaningful to older people is that it can be difficult to assess the lived experience of dignity in care, rather than the intention of service commissioners and providers to improve dignity in care. It is very difficult to measure how far someone feels respected, taken seriously, being valued and so on. Ticking boxes and providing traditional evidence of compliance with standards is no more likely to deliver the goods in future than it has in the past. Dignity in care is something that can only truly be assessed if the subjective experience of the person receiving care is given an appropriate weighting.

This approach to understanding and measuring dignity is at the heart of work that has been done at the University of Sheffield on the development of the combined assessment of residential environments (CARE) profiles – a tool to use in care homes (Faulkner, M. et al. 2006). It is a development of the ‘senses’ approach that formed part of the ‘Dignity on the Ward’ work by Help the Aged (see Appendix), and which was further developed by Nolan (Nolan 2004). The CARE profiles approach is based on the recognition that despite the well-known benefits of positive events for people’s own sense of well-being, little is known about the nature of these events as experienced by residents, relatives and staff in care homes. Also, there has been no reliable way to assess the frequency of events that are considered to be positive in care environments. Early testing of the CARE profiles suggests that they offer a useful way of identifying positive events in care homes, although, as yet, they may not adequately represent the experiences of people with cognitive impairment.

As we have seen, genuine measures of dignity in care have to be not only person-centred, but must also draw on sources of information that are, by their nature, harder to quantify, and rely, in part, on individual experiences and narratives as reality checks on other metrics. So the big question is: how can dignity in care be measured or assessed in ways that build on the development of Better Metrics, but which go beyond it?

Despite the difficulties in assessing dignity in care, there is a way forward. This does not seek
to replace the metrics used by the Healthcare Commission or those being developed by the Department of Health. Nor does it mean that it is impossible to attempt some measurements of subjective experience. For example, the answer to the question ‘Did you feel that your dignity was maintained?’ can be asked as is, or can be asked in a slightly different way of people who have received care over a period of time, to assess whether they felt that their dignity had been more or less well maintained in the past six months compared to the previous six months. Answers can also be taken together and understood alongside material from interviews, diaries and other methods for capturing personal experiences.

Also, at the risk of reinventing a very old wheel, some of what needs to be done echoes the ‘consumer audit’ approach that was in vogue some time ago and which asked questions that were specifically identified as important to service users (College of Health 1994). In line with this approach, a systematic user-focused approach to assessing dignity in care at regular intervals should be required of all providers of care to older people, and the results should regularly be made available.

The precise definition of appropriate and meaningful metrics of dignity in care must be developed with older people themselves, and it would be unwise to be too prescriptive here in the absence of the direct voices of older people.

The final bullet point in the list above begs the question ‘What objective indicators would be most suitable to provide a clear understanding of whether dignity in care was largely present or absent?’ In some instances, existing tools such as the Behind Closed Doors checklists (British Geriatrics Society 2006a) can be developed into user-focused metrics. In addition, the identification of sentinel user-focused indicators of dignity would be best seen as an additional perspective, to be given due weighting alongside some of the more conventional metrics that are already in place or in progress.

Judging by what we know to date about what older people have said, their priorities for sentinel dignity metrics may differ somewhat from the ‘official’ ones. For example, a metric for dignity in relation to mixed-sex wards would almost certainly require a different definition of a mixed-sex ward. A measure of dignified communication would probably give high priority to being addressed by one’s chosen title, and without condescension or patronising baby talk. A fundamental measure may relate to
whether an older person feels that they have been treated as an equal, with full regard for their autonomy and personal worth. In each instance, self-reported declarations of compliance by care providers would need to be supplemented by evidence from older people and their carers to check that dignity in care is real and not simply an aspiration.
Dignity on the Ward campaign (Help the Aged 1999)

During the late 1990s, Help the Aged led a very influential campaign, ‘Dignity on the Ward’, which continues to be influential today. The original campaign drew on the experiences of service users and staff at 24 acute hospitals in England. It was based on four key principles:

- **Valuing fundamental practice** – giving priority to the essential care needs of older people, such as help with personal hygiene, nutrition and going to the toilet; involving senior staff in direct care delivery.

- **Fostering stability while embracing challenge** – creating a stable ward team and a working environment in which innovation is valued and promoted.

- **Establishing clear and equitable therapeutic goals** – ensuring that older people have the same access to services as younger people, that clear treatment goals are set in consultation with older people and family carers and that these are regularly reviewed.

- **Commitment to an explicit and shared set of values** – developing an agreed philosophy of care which clearly identifies the standards of care and support expected for both patients and staff.

Dignity on the Ward set out ten challenges, as follows:

- Aiming for continuity of care
- Involving patients and their families
- Involving local communities
- Meeting the needs of older patients with confusion or dementia
- Meeting the needs of older people from ethnic minorities
- Helping people to come to terms with death on the ward
- Attending to small details for maintaining dignity

- Demonstrating commitment to developing practice
- Developing specialist roles
- Managing change effectively.

The findings of the investigations for Dignity on the Ward suggested that the most effective care for older people is that which creates an experience of well-being, both for older people and for those working with them. This can be considered in terms of six ‘senses’ which can provide a rationale for care delivery and also contribute to enhanced job satisfaction and morale for staff. These are:

- a sense of security;
- a sense of significance;
- a sense of belonging;
- a sense of purpose;
- a sense of continuity; and
- a sense of achievement.

Based on all of this, a number of recommendations were made.

**Practitioners** should:

- involve older people and their families in assessment, care planning and evaluation whenever possible;
- value family carers’ knowledge of the older person;
- seek regular feedback on the appropriateness of their care;
- take every opportunity to provide information and explanation; and
- try to provide the standard of care which they would like a close relative to receive.

**Multidisciplinary teams** should:

- consider approaches for involving older people and family caregivers more specifically in planning and evaluating programmes of care;
- take steps to guarantee that every older person has a named key worker for the duration of their stay and attempt to ensure...
that the older person has access to the same small group of carers whenever possible;

- ensure that older people have access to and receive care from senior and experienced members of the multi-disciplinary team, particularly nursing staff; and

- review the support offered to patients and staff following a death on the ward.

Managers should:

- ensure that systems for supporting staff development are in place, including appraisal, mentorship and clinical supervision;

- provide access to programmes of education and training and ensure that staff are able to attend through the use of flexible approaches such as voucher schemes allowing payment or time off in lieu;

- ensure that staff from all grades and disciplines receive communication-skills training involving older service users;

- provide training in the care of older people with confusion and dementia and access to specialists for advice and support;

- ensure that staff working in integrated care services have access to specialist expertise in the specific care needs of older people and that patients receiving care in specialist units should have swift access to staff in other medical and surgical specialities, should this become necessary;

- check that mechanisms are in place to facilitate consultations with local representatives of older people and family carers in relation to service developments;

- liaise with community groups representing the needs of older people from ethnic minorities to ensure that services are meeting the needs of these groups;

- review the current use of volunteers and identify opportunities for working with local charities to introduce extended volunteer programmes incorporating training and support;

- review the availability of recreational activities on acute hospital wards and consider the extent to which volunteers could be involved in offering such activities; and

- explore the need to establish schemes for easing the transition between hospital and home, such as discharge support teams and telephone follow-up.

These recommendations have had considerable influence and have mostly been implemented to some extent. The thinking behind the recommendations appears to have withstood the test of time, and to the extent that the recommendations are not fully implemented or are breached, they would still be a useful guide towards good practice. However, like so many other influential documents, the fact is that this one did not succeed in putting an end to undignified care, and the question remains why recommendations that are relatively uncontroversial (at least now) are still not fully implemented.

Not Because They Are Old (HAS 2000 Inquiry) (Health Advisory Service 1998)

The HAS 2000 inquiry was set up on 12 November 1997 by Frank Dobson when he was Secretary of State for Health. It followed the Help the Aged-backed Dignity on the Ward campaign in the Observer newspaper about the treatment of elderly people in UK hospitals. The report recommended action on several levels, including:

- NHS hospital chief executives to ensure proper standards of food and drink and clean sheets for all patients;

- work to begin on the preparation of clear standards for care of older people. Hospitals which do not meet the standards could face Department of Health intervention;

- £30 million to go to modernising accident and emergency departments by April 2000 to ensure that older people do not have to wait on trolleys;
investment in equipment to help older patients move around in hospital;

- a national patient survey to find out what patients think of their care;

- a long-term care charter for people in hospital and nursing and residential homes;

- a national service framework, setting standards of care, by April 2000;

- all trusts to have training plans for health workers by 2002, which include care of older people; and

- huge reductions in the number of mixed wards for older patients by 2002.

In answer to parliamentary questions on 25 January 1999, the then Minister of Health, John Denham, gave assurances that a Health Service Circular (HSC 1998/220) had been issued in November 1998 to all chief executives of health authorities and NHS trusts, along with a copy of the report _Not Because They Are Old_. This required chief executives of health authorities, in partnership with colleagues in NHS trusts and social services, to ensure that the findings of the report were considered when preparing joint investment plans for older people.

These joint investment plans were to be included in local health improvement programmes which would include both national and local priorities (House of Commons Hansard 1999).

**What has happened since the HAS 2000 report?**

In spite of the report having widespread press coverage and being a major focus of debate and action, some of the specific issues that concerned the HAS 2000 team have continued to be of significant concern.

Taking a wider view, it is evident that many of the concerns in _Not Because They Are Old_ have not been addressed. The list of inquiries and reports of serious shortcomings in services for older people where not only dignity but also safety and basic human rights have been compromised is depressingly long. Foremost among these is Rowan Ward. In October 2002, the Greater Manchester Strategic Health Authority contacted the Commission for Health Improvement (CHI) – the forerunner of the Healthcare Commission – to request an investigation into older age services at Manchester Mental Health & Social Care Trust. This followed allegations, in August 2002, of physical and emotional abuse of patients by care staff on Rowan Ward, an isolated facility housing older people with mental health problems.

Much has been written about Rowan Ward, including the CHI report on its findings (Commission for Health Improvement 2003). The Care Services Improvement Partnership later produced a document to share learning and provide information and useful contacts to colleagues in development centres, strategic health authorities, primary care trusts, local authorities and all organisations working to improve in-patient services for older people with mental health problems (Care Services Improvement Partnership/Department of Health 2005). It is evident from this and from many other reports that the HAS 2000 report, _Not Because They are Old_, was by no means the last word on treating older people with dignity.

**Essence of Care**

_Essence of Care_ (Department of Health 2001a), launched in February 2001, provides a tool to help practitioners take a patient-focused and structured approach to sharing and comparing practice. It has been widely used to enable health care personnel to work with patients to identify best practice and to develop action plans to improve care. The benchmarks that were developed for _Essence of Care_ were revised in 2003 and an additional area of benchmarking was added in 2006 (Department of Health 2006f). The benchmarks now cover ten areas of care:

- promoting health (new benchmark in March 2006)
communication between patients, carers and health personnel
continence and bladder and bowel care
personal and oral hygiene
food and nutrition
pressure ulcers
privacy and dignity
record-keeping
safety of clients with mental health needs in acute mental health and general hospital settings
principles of self-care.

All the sets of benchmarks are interrelated. For example, there are elements of privacy and dignity that link with continence and bladder and bowel care.

The Essence of Care benchmarking toolkit comprises:

- an overall patient-focused outcome that expresses what patients and/or carers want from care in a particular area of practice; and
- a number of factors that need to be considered in order to achieve the overall patient-focused outcome.

Each factor consists of:

- a patient-focused benchmark of best practice, which is placed at the extreme right of the continuum;
- a continuum between poor and best practice. The benchmark for each factor guides users towards best practice;
- indicators for best practice identified by patients, carers and professionals that support the attainment of best practice;
- information on how to use the benchmarks; and
- accompanying forms to facilitate documentation.

### Benchmarks for privacy and dignity

The benchmarks for privacy and dignity are of particular interest and are set out here.

<table>
<thead>
<tr>
<th>Factor</th>
<th>Benchmark of best practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Attitudes and behaviours</td>
<td>Patients feel that they matter all the time.</td>
</tr>
<tr>
<td>2 Personal world and personal identity</td>
<td>Patients experience care in an environment that actively encompasses individual values, beliefs and personal relationships.</td>
</tr>
<tr>
<td>3 Personal boundaries and space</td>
<td>Patients' personal space is actively promoted by all staff.</td>
</tr>
<tr>
<td>4 Communicating with staff and patients</td>
<td>Communication between staff and takes place in a manner which respects their individuality.</td>
</tr>
<tr>
<td>5 Privacy of patient – confidentiality of patient information</td>
<td>Patient information is shared, with consent, to enable care.</td>
</tr>
<tr>
<td>6 Privacy, dignity and modesty</td>
<td>Patients' care actively promotes their privacy and dignity, and protects their modesty.</td>
</tr>
<tr>
<td>7 Availability of an area for complete privacy</td>
<td>Patients or carers can access an area that safely provides privacy.</td>
</tr>
</tbody>
</table>
In all, while Essence of Care continues to be useful, and has led to valuable progress towards dignity in care, it has manifestly failed to put an end to the major lapses in dignity that continue to occur for older people in health and social care settings.

**National Service Framework for Older People**

Few documents about the care of older people have been as ambitious as the National Service Framework (NSF) for Older People (Department of Health 2001b). Launched by the Department of Health in 2001, and overseen by an energetic and respected National Clinical Director, Professor Ian Philp, it set out eight standards to improve the experiences of older people and their carers using health, social care, and other services. These standards focus on:

- rooting out age discrimination
- promoting person-centred care
- intermediate care
- general hospital care
- stroke services
- falls services
- mental health in older people
- promoting health and active life in old age.

There has also been an addition on medicines management.

While all the standards are relevant to dignity in care, Standard 2 on person-centred care is particularly important. This standard aims:

> to ensure that older people are treated as individuals and they receive appropriate and timely packages of care which meet their needs as individuals, regardless of health and social services boundaries.

The NSF explicitly addresses privacy and dignity, noting that:

> older people and their carers have not, however, always been treated with respect or with dignity.

Nor have they always been enabled to make informed decisions through proper provision of information about care across care sectors.

It sets out what managers and professionals must do to provide person-centred care, including:

- listening to older people;
- respecting their dignity and privacy;
- recognising individual differences and specific needs, including cultural and religious differences;
- enabling older people to make informed choices, involving them in all decisions about their needs and care;
- providing co-ordinated and integrated service responses; and
- involving and supporting carers whenever necessary.

The NSF for Older People also sets out standards for end-of-life care, which are relevant to dignity. These cover:

- information and communication – to facilitate choice about treatments and care options for older people and their carers;
- control of painful and other distressing symptoms – to anticipate, recognise and treat pain and distressing symptoms, and provide timely access to appropriate specialist teams, equipment or aids. There is evidence that older people are less likely to receive proper pain management;
- rehabilitation and support as health declines – to ensure that quality of life and independence is maximised, and that an older person can remain at home (if that is their wish) until death or for as long as possible, through providing therapy and personal care and housing-related support services;
- social care – to maintain access to safe and accessible living environments, practical help, income maintenance, social networks and information;
spiritual care – to recognise and meet spiritual and emotional needs through the availability of pastoral or spiritual carers, reflecting the faiths of the local population;

complementary therapies – to provide evidence-based complementary therapies that support emotional, psychological and spiritual well-being and help with symptom control;

psychological care – to anticipate, recognise and treat any psychological distress experienced by the older person, carer or their family; and

bereavement support – to ensure the needs of family, friends and carers are provided for, relieving distress, meeting spiritual needs and offering bereavement counselling.

In its progress report in 2004 on Standard 2 (Department of Health 2004), the Department of Health was upbeat about progress. It stated:

Although much remains to be done, there has been much progress in making both health and social services more focused on what users and carers want.

Specifically, it instanced progress with the Single Assessment Process, a reduction in mixed-sex wards and the inclusion of free continence services for self-funding residents of care homes providing nursing care. It also identified areas where further progress was required, and in many of those areas further progress has indeed been made.

A New Ambition for Old Age

Once again, we have to ask why standards of dignity are not universally met (or almost so) when so much effort and resource have gone into making care more person-centred. Presumably, these questions have also exercised politicians and policy-makers in the Department of Health, since they have gone on to publish A New Ambition for Old Age (Department of Health 2006h). This report outlined progress to date since the NSF in 2001. It highlighted:

- a steady increase in the proportion of older people receiving intensive help to maintain high quality of life independently at home rather than in residential care;
- delayed discharge from acute hospitals being reduced by more than two-thirds;
- older people now receiving access to treatment and services in greater numbers through tackling age discrimination;
- specialist services for age-related needs, such as stroke and falls, continuing to improve; and
- increasing numbers of older people taking advantage of health promotion opportunities: for example, stopping smoking.

However, it acknowledged that more needs to be done. In particular, it noted that there are still negative attitudes to older people, and it stated the Government’s rather modest ambition that within five years, older people and their families will have the confidence that in all settings older people will be treated with respect for their dignity and human rights. In order to address this and the other areas where progress needs to be made, it introduced ten programmes under three themes: Dignity in Care, Joined-up Care and Healthy Ageing.

Within the Dignity in Care theme, the two programmes (entitled Dignity in Care and Dignity at the End of Life) aim to strengthen activities in the familiar areas where dignity standards are still frequently not met:

- nutrition and the physical environment;
- developing skills, competence and leadership in the workforce;
- assuring quality by working with the inspectorates and regulators;
- ensuring dignity for those with mental health problems;
- ensuring dignity at the end of life;
- equalities and human rights; and
- championing change.
**Living Well in Later Life**


The three inspectorates worked together to provide a comprehensive assessment of services for older people five years after the introduction of the National Service Framework (NSF) for Older People. The report found that services have improved since the March 2001 publication of the Government’s ten-year NSF for Older People. However, this progress was not evident consistently across the country and improvement in some areas has been slow. At this halfway stage, none of the communities inspected had reached all government-set milestones to enable them to meet the standards in the NSF.

On the positive side, the report found:

- improvements in how most public services are addressing age discrimination. All communities inspected had taken steps to ensure that policies and eligibility criteria for access to services did not discriminate against older people;
- more people who have had a stroke have access to good-quality hospital care than ever before. But more still needs to be done to improve rehabilitation outside hospital and access to specialist units; and
- more people are supported to live at home. There is a reduction in the number of older people admitted to care homes, with health and social care services supporting more frail older people to live independently.

However, the report also found a number of areas of concern, including evidence of a lack of dignity and respect in the way older people are treated when in hospital. Basic needs were not always met, with some patients not getting the right food, assistance with eating or help going to the toilet. Many older people experienced poorly managed discharge after being rushed through the system, repetitive moving from one ward to another to free up surgical beds, and having meals taken away before they can eat them because of a lack of support at mealtimes.

**National Minimum Standards**

The Department of Health sets national minimum standards in a number of areas and the Commission for Social Care Inspection (CSCI) regulates social care services in accordance with these and other regulations. The two sets of minimum standards that are most relevant to dignity in care for older people are National Minimum Standards – Care Homes for Older People (Department of Health 2003a) and National Minimum Care Standards – Domiciliary Care (Department of Health 2003b).

Standard 10 of the care homes standards relates specifically to the arrangements for health and personal care to ensure that service users’ privacy and dignity are respected at all times, with particular regard to:

- personal care-giving, including nursing, bathing, washing, using the toilet or commode;
- consultation with, and examination by, health and social care professionals;
- consultation with legal and financial advisers;
- maintaining social contacts with relatives and friends;
- entering bedrooms, toilets and bathrooms; and
- following death.

Standard 10 also sets out standards for other aspects of dignity, including:

- service users having easy access to a telephone for use in private and receiving their mail unopened;
service users wearing their own clothes at all times;

all staff using the term of address preferred by the service user;

all staff being instructed during induction on how to treat service users with respect at all times;

medical examination and treatment being provided in the service user's own room; and

screening being provided, where service users have chosen to share a room, to ensure that their privacy is not compromised when personal care is being given or at any other time.

Standard 11 sets out a standard for dying and death that states:

service users are assured that at the time of their death, staff will treat them and their family with care, sensitivity and respect.

The national minimum standards for domiciliary care (Department of Health 2003b) has two standards that are particularly relevant to dignity.

Standard 8 on privacy and dignity is worth quoting in full:

(8.1) Personal care and support is provided in a way which maintains and respects the privacy, dignity and lifestyle of the person receiving care at all times, with particular regard to assisting with:

- dressing and undressing;
- bathing, washing, shaving and oral hygiene;
- toilet and continence requirements;
- medication requirements and other health-related activities;
- manual handling;
- eating and meals;
- handling personal possessions and documents; and
- entering the home, room, bathroom or toilet.

(8.2) Care and support is provided in the least intrusive way at all times.

(8.3) Service users, their relatives and their representative are treated with courtesy at all times.

(8.4) Service users are addressed by the name they prefer at all times.

(8.5) Care and support workers are sensitive and responsive to the race, culture, religion, age, disability, gender and sexuality of the people receiving care, and their relatives and representatives.

Standard 9 on autonomy and independence is also relevant as it sets out what is required to enable service users to make decisions in relation to their own lives – providing information, assistance, and support where needed.

If these standards were observed fully, many of the reported breaches of dignity in care would no longer occur. Unfortunately, the experiences of older people and their carers (not infrequently supported by the regulators and inspectors) indicate that there is still a long way to go.


The Commission for Social Care Inspection’s (CSCI’s) second annual report on the state of social care in England (Commission for Social Care Inspection 2006a) makes a comprehensive assessment of care services for both adults and children. Substantial parts of the report are relevant to dignity in care. In line with many other official reports, CSCI notes some significant improvements and progress, but also notes that over the last year people have continued to express concerns about the gap between policy aims and the reality of their experiences.

One of several important issues raised by CSCI is that thresholds for accessing services are
The Challenge of Dignity in Care

High. For two-thirds of councils, the threshold for care-managed services was set at ‘substantial’ in 2005–6 and a number of councils were expecting to raise their eligibility thresholds in 2006–7. This could well undermine the ability of older people to maintain their dignity at home. The situation is compounded by a lack of research, to date, on what happens to those who, for whatever reason, are not eligible for services or choose to fund their own care services. However, CSCI has current plans to commission research to address this lack of information.

CSCI also notes that there are still some home care and residential services that do not meet all the national minimum standards. Improvement against standards has slowed down.

Standards for Better Health

In 2006 the Department of Health published Standards for Better Health (Department of Health 2006g). It describes 24 essential or ‘core’ standards that all healthcare organisations in England that treat NHS patients should be achieving, and 13 developmental standards that they should be working towards achieving in the future. By assessing compliance against these core standards as part of the annual health check each year, the Healthcare Commission gets an overview of how well each organisation is achieving the general standards of care that the Department of Health requires.

The core standards cover seven areas of activity:

- safety
- care environment and amenities
- clinical and cost-effectiveness
- governance
- patient focus
- accessible and responsive care
- public health.

The Healthcare Commission annual health check also assesses the services that healthcare organisations provide, paying particular attention to the experiences of children, older people, people with long-term conditions, and people with mental health problems.

Two standards are particularly relevant to dignity and privacy:

- C13a Healthcare organisations have systems in place to ensure that staff treat patients, their relatives and carers with dignity and respect.
- C20b Healthcare services are provided in environments which promote effective care and optimise health outcomes by being supportive of patient privacy and confidentiality.

The Healthcare Commission’s interest in dignity has been heightened by the report Living Well in Later Life (Healthcare Commission, Audit Commission and Commission for Social Care Inspection 2006), in which it was involved. Also, in 2006 the Commission published a survey of some 80,000 adult in-patients which highlighted concerns. Overall, 80 per cent of people said they were ‘always treated with dignity and respect’. In some organisations this figure was as high as 96 per cent; in others as low as 61 per cent. Of those needing help to eat meals, a fifth of those surveyed – almost 40 per cent – said that they either never (18 per cent) or only sometimes (21 per cent) received help. In addition, in a recent report on NHS complaints referred to the Commission, approximately 7 per cent related to nursing care. Of these, the most prevalent complaints were regarding the nutrition of patients. These included complaints about poor-quality food, lack of help with eating and patients being given food they could not eat. Other common complaints about nursing related to the attitudes of staff and the dignity of patients.
Dignity visits 2007

In 2007, the Healthcare Commission began to carry out a review of acute services to ensure that older people are treated with dignity and respect. It selected 23 acute NHS trusts for inspection. During the inspection visits, it examined documentary evidence, observed wards and interviewed staff at all levels, checking that hospitals comply with standards on treating older patients with dignity and respect. It also looked at the results of patient surveys, as well as information about complaints and the quality of the environment, including levels of privacy.

Dignity in Care public survey, October 2006

In October 2006, the Department of Health published the results of its online public survey on Dignity in Care (Department of Health 2006a), set up to hear directly from the public about its own experiences of being treated with dignity by care services, or about the care individuals had seen being provided to others. Four hundred people took part, of whom approximately half were professional staff working in health or social-care settings. The survey asked the following questions:

Q1. Have you experienced, or do you know of, a care service that respects a person’s dignity?

Q2. Have you experienced, or do you know of, a care service that does not respect a person’s dignity?

Q2a. Were you able to do anything about that care service? If yes, what did you do?

Q3 & 5 Tell us the most important thing providers of care services and/or government can do to make sure services respect people’s dignity

Q4. What one thing can government do to make sure care services respect people’s dignity?

Q6. Are there any general comments on this subject that you would like to make?

Main issues raised

- There is no clarity about what dignity is and what minimum standards for dignity should be (see below).
- It is difficult to make a complaint about services
- It is hard to understand how to make a complaint
  - Once you have lodged a complaint, little is done about it
  - People are scared to complain.
- People are often not listened to or treated as an individual
  - For example, people are cared for as a group or are all got ready for bed at the same time.
- People often do not have enough privacy when receiving care
  - Privacy and dignity complement each other.
- There is not enough assistance available to service users to help them eat meals
  - There is a lack of support and assistance to eat meals
  - Mealtimes are seen as a procedure to be got over quickly, rather than as a social event.
- There is insufficient access to lavatory and bathroom facilities
  - Too little help is available when needed
  - People are encouraged to use commodes so that staff do not have to help them to the bathroom
  - Access to bathing is restricted to certain days
- People care about how they are addressed by care staff; for example, wanting to be addressed more or less formally.
- It is important for service users to maintain a respectable appearance when they are receiving care
  - Problems with laundry and clothes being damaged do exist.
- Having stimulating activities and a sense of purpose (when in a care home or at home alone) are important.
Some care staff have difficulties communicating with or understanding service users because of their language skills.

People do not know how to access advocacy services and there are insufficient advocacy services for vulnerable adults
- Advocacy services could help improve the complaints system
- Advocacy is particularly useful for accessing Direct Payments.

In addition, a smaller number of comments were made about:
- being placed in mixed-sex facilities, which makes many people feel uncomfortable; and
- language barriers between care staff and service users.

The report of the survey made some unsurprising recommendations, including:
- making it easier to complain;
- improving the inspection and regulation of the service; and
- raising awareness and understanding of dignity in care (including in the training and awareness of staff).

The Dignity Challenge, 2006

On 14 November 2006 Ivan Lewis MP, Parliamentary Under-Secretary of State for Care Services, announced a new campaign to raise the profile of treating people receiving care services with dignity (Department of Health 2006d).

He acknowledged that emphasis on throughput (improved access and reducing waiting lists) had sometimes been at the expense of the quality of care provided. This campaign aimed to redress the balance and put dignity at the heart of care by adopting a number of approaches, including:
- raising awareness of dignity in care and inspiring local people to take action;
- spreading best practice and supporting people and organisations to drive up standards; and
- rewarding and recognising those who make a difference and go the extra mile.

The Minister invited people to take up the Dignity Challenge, which states that high-quality care services that respect people’s dignity should:

1. have a zero tolerance of all forms of abuse;
2. support people with the same respect you would want for yourself or a member of your family;
3. treat each person as an individual by offering a personalised service;
4. enable people to maintain the maximum possible level of independence, choice and control;
5. listen and support people to express their needs and wants;
6. respect people’s right to privacy;
7. ensure people feel able to complain without fear of retribution;
8. engage with family members and carers as care partners;
9. assist people to maintain confidence and a positive self-esteem; and
10. act to alleviate people’s loneliness and isolation.

The Dignity Challenge is backed up by a series of dignity tests that can be used by services to see how they measure up.

At the same time, the Minister also announced:
- a £67 million capital investment to help local authorities improve the physical environment of care homes;
- an online Dignity in Care Practice Guide (Social Care Institute for Excellence 2006);
- a partnership with Investors in People (IIP) UK;
- a programme of service improvement support to be delivered locally; and
- support for this agenda from the health and social care regulators.

He also asked that overview and scrutiny
committees build time into their work programmes to review local commissioning practices and service provision against the expectations set out in the Dignity Challenge.

**Dignity Champions**

To take forward the Dignity Challenge, the Minister also launched the concept of Dignity Champions (Department of Health 2006e) – a role which in February 2007 subsumed the previous role of Older People’s Champions. Anyone who was committed to taking action to improve dignity in care was invited to become a Dignity Champion. Their role was to:

- put dignity on the local agenda: for example, by encouraging local network meetings, encouraging organisations and teams to discuss dignity, getting media coverage/stories on dignity and distributing the dignity card;
- take up the Dignity Challenge: for example, by challenging services that do not respect dignity and changing own working practices or those of one’s organisation; and
- share what works.

**Dignity in care and human rights**

Increasingly, dignity is being understood as an aspect of human rights. This point is made in a recent submission by the British Geriatrics Society to the UK Parliament’s Joint Committee on Human Rights (British Geriatrics Society 2006b). For example, it describes infringements of the human rights of older people in care homes that raise issues under Section 3 (prohibition of inhuman and degrading treatment), Section 8 (right to respect for private life) and in extreme cases also Article 2 (right to life). Many of the aspects of poor care which it identifies as undermining human rights would certainly be generally understood to be incompatible with dignity.

Help the Aged also submitted a comprehensive response to the inquiry by the Joint Committee on Human Rights (Help the Aged 2007). This response highlighted a number of ways in which the human rights of older people are breached in both healthcare and social-care settings. It also set out clear recommendations on ways in which the human rights of older people can be protected when they are in need of or in receipt of care.

It is likely that more challenges will be made about poor and undignified care by older people and other users of health and care services in the future. Indeed, being treated with fairness, respect, equality and dignity (the so-called FRED principles) is at the heart of the human rights approach.

There are indications that older people do not necessarily wish to use the courts to enforce their human rights (although some do), and those who wish to pursue legal redress will need a lot of support to do so. However, older people may well increasingly use the language and concepts of human rights to negotiate with and challenge services (Butler 2006). Furthermore, the legal requirement that all public bodies act compatibly with fundamental rights means that commissioners and regulators must take positive steps to ensure that service providers uphold individual rights in the delivery of services. Human rights are, therefore, integral to developing effective metrics.

Perhaps the ‘high point’ of recognition of the extent of the application of human rights to disabled people in domestic law has been in the case of R (A & B) and others v East Sussex County Council and the DRC (no. 2). This case concerned two profoundly learning and physically disabled adults who were unable to access either swimming or horse-riding, both of which they seemed to enjoy, because of manual handling restrictions. The judge, Mr Justice Munby, considered the relevance of Articles 3 and 8 of the Convention on Human Rights and made very positive findings for disabled people, which would of course be equally applicable to older people in similar circumstances.

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He confirmed that the concept of ‘respect’ for family and private life includes, in some circumstances, a duty to take positive steps to promote private and family life. He also confirmed that ‘physical and psychological integrity’ are part of private life protected under Article 8. He said that this involved two concepts:

(i) human dignity, also the concept at the core of Article 3. An enhanced degree of protection may be called for when the human dignity of a disabled person is at stake. In order not to discriminate, it may be necessary to treat a disabled person differently because their situation is different from that of the able-bodied.

(ii) ‘the right of the disabled to participate in the life of the community’ and to have what has been described (in the Botta v Italy case) as ‘access to essential economic and social activities and to an appropriate range of recreational and cultural activities’. This is matched by the positive obligation of the state to take appropriate measures designed to ensure to the greatest extent feasible that a disabled person is not ‘so circumscribed and so isolated as to be deprived of the possibility of developing his personality’.

Mr Justice Munby also said that Article 3 might well be engaged, for instance, if a failure to lift meant that A or B was left sitting in bodily waste. Article 2 (the right to life) could be engaged if they slipped under the water in the bath and could be saved only by being lifted out.

The judge recognised that care assistants have corresponding rights and a balancing exercise was needed to ensure that risk to staff was reduced as far as possible, taking into account the rights of the disabled individuals.

There is a debate about the implications of this case and some doubts have been expressed about the suggestion that Convention rights can result in any reduction in workers’ safety. However, the importance of the case is in the breadth of the definition of rights inherent in the concept of private life and the correlation between dignity and Articles 3 and 8 of the Convention.
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Fighting for disadvantaged older people in the UK and overseas,
WE WILL:

**COMBAT** POVERTY wherever older people's lives are blighted by lack of money, and cut the number of preventable deaths from hunger, cold and disease.

**REDUCE** ISOLATION so that older people no longer feel confined to their own home, forgotten or cut off from society.

**CHALLENGE** NEGLECT to ensure that older people do not suffer inadequate health and social care, or the threat of abuse.

**DEFEAT** AGEISM to ensure that older people are not ignored or denied the dignity and equality that are theirs by right.

**PREVENT** FUTURE DEPRIVATION by improving prospects for employment, health and well-being so that dependence in later life is reduced.