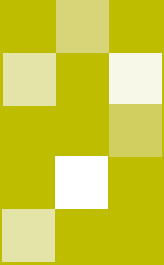


Walk a mile in my shoes

Scrutiny of dignity and respect for individuals in
health and social care services: a guide





“

*If I could be you and you could be me for just one hour
If we could find a way to get inside each other's mind...*

*Walk a mile in my shoes, walk a mile in my shoes
And before you abuse, criticize and accuse
Walk a mile in my shoes.*

”

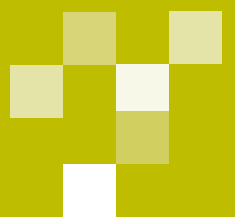
Joe South

“

*Support people with the same respect you would want
for yourself or a member of your family*

”

The Dignity Challenge: point 2



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Foreword

Like everyone else, I have experienced the health and social care system, both as a (very occasional) user of services, and more often through family and friends. I know that respect and dignity – being treated as an individual – is very important to people. And I believe that this can significantly affect their wellbeing and their recovery from illness.



I believe that elected members of local authorities, in their scrutiny role, are making a real difference to how people who use health and care service are treated, not only by exposing actions and practices that are disrespectful, but also by celebrating good practice where they find it. But I also know that there is much more that Overview and Scrutiny Committees can still do, by continuing to raise these issues in the course of their work.

This guide is designed to assist Overview and Scrutiny Committees and others in discussing what dignity is, why it matters and how to assess whether an organisation or service treats the people whom it serves with dignity and respect. The key messages that I hope will emerge from this document are that:

- being treated with dignity and respect is consistently one of the **most important issues** for people using services and lack of dignity and respect is one of the top reasons for complaints
- the NHS review, High Quality Care for All emphasises that treating people as individuals, and therefore with dignity and respect, is a key part of **quality** services; the NHS Constitution gives people the **right** to be treated in this way; and the Comprehensive Area Assessment will provide citizens and communities with a better picture of **outcomes that matter**, including dignity and respect
- issues of dignity should be embedded in the **commissioning** of health and social care and other public services and scrutiny should always take commissioning as its starting point – if dignity and respect are missing from commissioning it is unlikely that providers of services will get them right either
- care organisations and services should always have **policies** in place to promote dignity and respect but Overview and Scrutiny Committees will need to ensure they have **evidence** that these are working in practice on the “front line” and reflected in the experiences of individual service users
- equally, individual health and social care practitioners who champion dignity in care need to be supported by strong **leadership**.

I am delighted that many councillors have already pledged to become Dignity Champions. I hope that the experience of participating in scrutiny reviews which prioritise issues of dignity and respect will encourage even more to sign up as Dignity Champions for the area they represent – to ensure the issue of dignity moves to the heart of all NHS and care services.

*Councillor David Rogers
Chair, Health and Wellbeing Board
Local Government Association*

Preface and acknowledgements

This guide is intended to assist local authority Overview and Scrutiny Committees (OSCs) in reflecting dignity issues throughout their work.

We hope that the guide will assist them in a number of ways to help raise awareness and understanding of dignity and respect for individuals who are receiving health and social care services.

Using the guide, OSCs should be in a position to:

- review local leadership and partnerships to judge whether services respect the dignity of service users
- promote dignity and respect for individuals and the role of the OSC
- help ensure local health and care services are commissioned and delivered with dignity as a central aspect of care; and that an approach to dignity is embedded at a strategic and corporate level as well as at the frontline
- gather local intelligence and provide evidence which can be reflected in local reviews of services by the Care Quality Commission (CQC) and in the Comprehensive Area Assessment (CAA).

The intended audience for the guide is primarily Chairs and Members of OSCs and the local authority officers supporting overview and scrutiny. We hope that this will not only include OSCs with a specific health and social care remit or those scrutinising issues relating to older people. Dignity is an important issue for all users of all public services and, as such, should be part of local authority overview and scrutiny in many different areas, including housing services, transport and travel, leisure and cultural services. The intended audience therefore includes unitary, county and district councils as well as local authority and NHS staff and members of governing bodies, LINKs' members and Dignity Champions.

The guide was written by Fiona Campbell with the help of a Steering Group, to whose members, listed below, we are grateful for their time and effort.

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Caroline Coombes, Overview and Scrutiny Lead, Bradford Metropolitan District Council

Karen Dooley, Dignity in Care Campaign Manager, Department of Health

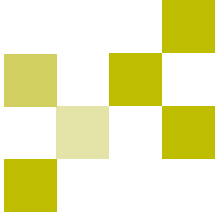
Anna Gaughan, Regional Dignity Lead, North West Improvement Partnership, chair of Steering Group

Cllr Shelagh Marshall, Yorkshire Futures and North Yorkshire County Council

Jan Potts, Dignity, Prevention and Early Intervention Lead, Yorkshire and Humber Improvement Partnership

Alison Williams, Health Policy and Scrutiny Officer, Warrington Borough Council.

A draft of the guide was tested with focus groups of overview and scrutiny councillors from Bradford Council and Warrington Council, to whom we are also grateful for their time and comments. Thanks also to Caroline Coombes, Bradford Council and Alison Williams, Warrington Council for arranging the focus groups and to Ken Clemens, Age Concern,



Cheshire for gathering feedback from local LINK members on an earlier draft of the publication.

The guide is a legacy product from the Dignity Beacon Award (2008-9). It was sponsored by the Department of Health, the Centre for Public Scrutiny, the Improvement and Development Agency for Local Government, the North West Joint Improvement Partnership and Yorkshire and Humber Improvement Partnership working with partners from Future Years, Age Concern Cheshire, Warrington Borough Council and the City of Bradford Metropolitan District Council.

The guide is supported by a presentation and set of exercises which can be used by OSCs to inform their work on dignity and respect. These can be downloaded from the Centre for Public Scrutiny website www.cfps.org.uk

A word about language

We all know it's not true that "sticks and stones may break my bones / but words will never hurt me". Words can hurt a lot and, used insensitively, can undermine people's dignity and self-respect. Even something as simple as whether a person is addressed by their first name or their title and surname can make a difference. The steering group thought long and hard about how to refer to the people who are the subject of this guide. Since dignity is very much about respecting the unique viewpoint and experience of each individual, we felt it important to emphasise the individual rather than the group they belong to. So we have generally talked about people first and groups second, for example, "people with dementia". Sometimes this would make for an artificial and cumbersome way of writing, so, for example, we talk about "older people" rather than "people who are older". Sometimes, indeed, it is membership of a group that is at the root of how people are treated, as when people are discriminated against by sex, race or age. We know also that people who belong to different groups have strong feelings about how they are described, so our use of language may not satisfy everyone. The important message for scrutiny of dignity issues, we believe, is to think about language as an aspect of dignity, to try not to label people too hastily; and to try to respect the way that people prefer to be referred to themselves.



1

Introduction

What is dignity and why does it matter?

According to dictionary definitions, dignity is the quality or state of being worthy of esteem or respect. This means that it is a quality possessed by all human beings, since all are worth respect. But dignity is also about how people are treated. If you treat someone disrespectfully, then you take away their dignity. We often talk of treating someone with dignity, as shorthand for treating them as though they are worthy of respect.

One important form of respect is self-respect. If you are not treated with respect by others, it is hard to hold onto your self-respect. It is hard to keep your sense of yourself as an autonomous person with rights to the kind of things that contribute to self-respect, like privacy. So, as the Social Care Institute for Excellence puts it,

“dignity consists of many overlapping aspects, involving respect, privacy, autonomy and self-worth”. (SCIE Guide 15)

Because all of these aspects are so important to our sense of our own and others’ full humanity, the loss of dignity is a very serious thing for any human being, young or old.


The importance of dignity as a fundamental aspect of an individual’s humanity is recognised in human rights legislation. The very first sentence of the Universal Declaration of Human Rights says that “recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world.” The UK Government’s stated purpose in introducing the Human Rights Act was to promote a culture of respect for these rights, making them a feature of everyday life.

Dignity and respect in health and social care

One of the times at which people are most in danger of losing their dignity and their self-respect is when they need help with health and social care. By their nature, health and social care services are provided when people are most vulnerable – when they are feeling at their weakest, when they are afraid and when they have to expose the most intimate and personal parts of themselves (their bodies and their minds) to inspection and handling by others.

Most of the time, most of us carry round with us a kind of protective shell: we cover our bodies with clothes that indicate how we want to be perceived by others; we protect our minds and our most private inner selves by concealing many thoughts and emotions; and we are usually able to control, to a considerable extent, how much of these we reveal, depending on how close we feel to the people we are with.

When we seek or need health and social care, we have to allow some of this protective shell to be breached to enable others, often strangers, to understand and help meet our needs. We may have to remove our clothes and allow others to examine our bodies and help us with our intimate bodily functions. Or we may have to reveal feelings and experiences that we would normally keep private. In these circumstances, because we are so vulnerable to the loss of our dignity, it is all the more important that it is recognised and protected.



In this guide, we will use the definition of dignity in care given by the Social Care Institute for Excellence:

“Dignity in care means the kind of care, in any setting, which supports and promotes, and does not undermine, a person’s self-respect, regardless of difference”

(SCIE Guide 15)

We take the phrase “regardless of difference” to refer to any of the ways in which individuals and the groups they belong to differ from each other. This includes age, gender and sexual orientation, race, nationality, religion and disability. Many of the policy documents written about issues of dignity in care use examples and case studies about the treatment of older people. This is partly because the majority of people using health and care services are older. Unfortunately, also, research has highlighted many instances in which older people have not been treated with the dignity and respect that is their right. But of course, it is not only older people who are entitled to dignity. Everyone is, including children and young people. And some of the most vulnerable groups in this respect, which have also been highlighted by research, include people with learning disabilities, people with physical disabilities, people with mental health problems, people with dementia, people with terminal illnesses and people from minority ethnic cultures – all of whom can be of any age.

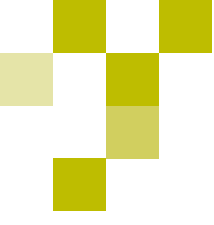
This publication is about services relating to adults and does not cover issues of dignity and rights specific to children and young people because there are different administrative systems, legislation and national policy (under the overall heading of *Every Child Matters*) for this group, which would require a lengthy separate discussion to do them justice. However, one group it is particularly important to highlight when thinking about adults is young people leaving local authority care and those “in transition” from children’s services to adults’ services. The personal transition from childhood to adulthood can be a time when young people particularly need to “stand on their dignity” as we say; and the quality of care services for young people receiving them can make a big difference to this.

Loss of dignity and lack of respect for individuals can lead to downright abuse. This guide does not attempt to cover issues of abuse, although the section on further information points to useful sources on this topic.

The need for greater dignity and respect is consistently highlighted by people using health and social care services; and lack of dignity and respect is one of the most cited reasons for complaints made about these services (Woolhead, 2004). So it clearly matters a lot to people who use services. And since people’s sense of self worth is so closely related to their wellbeing and resilience, dignity is closely related to quality of care. Promoting dignity and respect for individuals must be at the very heart of good quality care and service delivery – it is not an optional extra.

What can scrutiny add?

Since dignity is consistently cited as a high priority for service users, OSCs who investigate the issue will undoubtedly be responding to an issue of importance to their residents. Dignity is not a highly technical issue – although it may be difficult to define precisely, we all know when we or someone we care about has not been treated with dignity or respect. At the same time, it requires considerable sensitivity and an exploration in some detail to establish whether an organisation or service is one which embodies dignity and respect for individuals. Listening to the experience of health and social care service users and their relatives and



carers is a hugely important source of evidence on such a personal issue. All of this makes it a central and appropriate topic for OSCs – and there are notable examples where OSCs have been proven to be effective in this area. Some of these are briefly described in the ‘scrutiny review’ boxes throughout this guide.

Almost all the scrutiny work so far relating explicitly to dignity has been about services for older people. OSCs are now beginning to think about dignity and respect in relation to other groups. The examples in the ‘dignity in care’ boxes throughout the text show the huge range of activity across the country – we hope that these examples will spark some ideas among OSCs about how they might investigate and promote good practice in their own areas.

Experience to date shows that where OSCs have already looked at dignity issues they can contribute to ensuring that dignity in care is embedded in service planning and delivery. One example is that of the London Borough of Hackney whose Health Scrutiny Committee recommended the widespread adoption and use of a Dignity Code. It is clear that this recommendation has been highly influential and the Code now informs both commissioning and providing of health and social care in the Borough.

Overview and Scrutiny Committees already have a track record in raising sometimes overlooked issues on behalf of those whose voices are seldom heard. Sometimes also, their members can bring a perspective to an issue that may go straight to the heart of what matters to ordinary people. A simple example is that of mixed-sex wards in hospitals. Research has shown that, whereas NHS managers count wards as “single-sex” where there are bays with members of only one sex, the general public perceives them as mixed-sex if there are people of the two sexes in different bays in the same ward. This is seen by many people as an issue of dignity and is just the sort of issue which Overview and Scrutiny Committees can raise and bring a commonsense view.

Similarly, commissioners and providers of health and social care have tended to think of specific services or institutions when considering the quality of services. But, as councillors know, most people who are finding their way through the health and social care system don’t distinguish carefully between its different components – what matters to them is the quality of service *as a whole*. Unfortunately, it is precisely at the interface between different sectors or services that quality of care and the factors that impact positively on dignity can break down. This is just the sort of area to which the scrutiny function can bring added value by looking across the whole “care pathway” from the perspective of an individual who is traversing it.

The care pathway can even extend beyond traditional health and social care services. For example, the suitability of people’s housing and their access to their neighbourhood – public transport, shops, meeting places, green spaces, leisure facilities - can make a big difference to their quality of life and to their dignity. The local authority wellbeing power provides a remit for OSCs to look holistically at all of these issues through the “dignity lens”.

OSCs are also in a good position to raise the profile of the issue locally, as, for example, North East Lincolnshire Dignity in Care Select Committee did, with an article in the Grimsby Telegraph. As an authoritative voice on the quality of care in their area and as a channel for people who use services and people who care for them to make their own voices heard, OSCs are ideally placed to present evidence to the Care Quality Commission and to inform the Comprehensive Area Assessment. In sum, they have an opportunity to influence the agenda locally and drive forward better quality services.

2. The national context



The Dignity in Care Campaign

Dignity in Care is far higher up the policy agenda for care services than ever before. Services are now operating against a policy backdrop that places quality, patient experience, dignity and respect at the heart of care. Dignity features in key performance frameworks including the NHS Operating Framework and the *National Indicator Set* and is a consistent theme in the key strategies including: *Living Well with Dementia – a National Dementia Strategy* (February 2009), *High quality care for all adults at end of life* (July 2008) and *Carers Strategy – Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own* (June 2008).

The direction of travel of the *NHS Next Stage Review “High quality care for all”* places a strong emphasis on dignity and respect and the new *NHS Constitution* includes the right for patients to be treated with dignity and respect. Key organisations representing service users and care providers are taking action to promote dignity in care. For instance, the *Care Quality Commission* has included dignity and respect as one of its six key area of inspection.

Launched by the Department of Health (DH) in November 2006, the ‘Dignity in Care Campaign’ (www.dignityincare.org.uk) aims to end tolerance of care services that do not respect people’s dignity by:

- Raising awareness and stimulating a national debate around Dignity in Care
- Inspiring and equipping local people to take action
- Rewarding and recognising those who make a difference

The Campaign was originally launched specifically to promote dignity for older people but its focus is gradually being extended to all those receiving health and social care services.

As part of the Dignity in Care Campaign, the Dignity Challenge was issued. Based on consultations with service users, carers and professionals, it lays out the national expectations of what constitutes a service that respects dignity. It focuses on ten different aspects of dignity – the things that matter most to people. As such, it will be an important starting point for any scrutiny relating to dignity issues.

The Dignity Challenge

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.
10. act to alleviate people’s loneliness and isolation.

Dignity Champions

The Department of Health has set up a network of well over 10,000 Dignity Champions, people who are “committed to taking action, however small, to create a care system that has compassion and respect for those using its services”. The role of Dignity Champions varies depending on their knowledge and influence and the type of work they do. Members of OSCs may already be Dignity Champions or may consider becoming Dignity Champions in the course of their scrutiny work.

Dignity Champions can be a very useful source of advice and evidence for local authority OSCs. The Department of Health has set up a database of several thousand Dignity Champions (see section on further information below). You can search this database for Champions in your area with different roles and particular interests.

Local Involvement Networks

All local authority scrutiny committees concerned with health and social care issues will have made links with the Local Involvement Network (LINK) for their area. LINKs will almost certainly have some members who have signed up as Dignity Champions, but even where LINKs do not include Dignity Champions, LINKs members will be important sources of experience and evidence in any scrutiny relating to dignity in care. LINKs members, as users of services, as carers and as members of different communities of interest and identity will be able to bring an invaluable range and a richness of experience to scrutiny work. Additionally, with their “enter and view” power to visit providers of both health and social care, LINKs can make an important contribution to the information on dignity available to OSCs.

Some health OSCs have co-opted LINKs members onto their committees, others use LINKs members as expert advisers for particular scrutiny reviews and others have begun to take evidence from LINKs in the course of carrying out reviews. The host organisations supporting LINKs have a particular remit to assist their LINKs to reach out to minority communities and those whose voices are seldom heard. This is important in relation to dignity, as these groups can sometimes suffer the greatest indignities, due to lack of access to appropriate services and lack of understanding of their needs and the sources of their self respect.



3

Scrutiny – asking the right questions

Issues that should be covered in any scrutiny review of dignity

Corporate issues

What sort of leadership is given on dignity?

How is dignity embedded in governance? (Eg how are dignity issues reported to the Board/Executive, how often, in what form?)

How are people who use the service(s) involved in developing strategies on dignity and in the training and development of leaders and staff?

What do external assessments (eg those of the Care Quality Commission) say?

Procedural issues

What policies are in place to ensure that dignity and respect are central to care?

What systems are in place to support these policies? What training is made available to staff on the policies and how to manage their implementation?

Collecting evidence

How does the organisation or service monitor the implementation of its dignity policies?

How are people who use the service(s) and their relatives and carers involved in monitoring aspects of dignity?

Can the Local Involvement Network provide any evidence of the experience of people using services?

Learning from experience

Is systematic incident reporting used to inform reviews of service(s) and improve them?

What is the “whistleblowing” policy, how is it promoted and used, are there any examples of its use?

What use is made of complaints reporting and feedback from people using services and their carers to learn and improve?

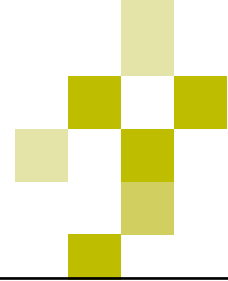
Who is responsible at different levels of the organisation to learn from mistakes?

Can the organisation/service provide examples of learning from mistakes, showing that it is a “learning organisation”?

As the discussion in the previous sections suggests, and as readers’ own experiences will tell them, there are many components to dignity and respect and the focus will shift depending on what aspects of health and social care services are being scrutinised. As with any scrutiny review, it will be important for OSCs considering dignity issues to be clear from the outset what questions they are seeking to answer in the course of a review. For example, it will be important to be clear about the following when thinking about the kinds of outcomes you are seeking from a review.

Is your review about the commissioning or about the delivery of services?

If you are looking at commissioning issues, your main concern will be to understand how and to what extent dignity is reflected in overarching commissioning strategy and how this translates into individual contracts for commissioned services. Whereas if you are

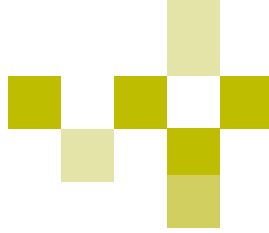


looking at how services are delivered, you will want to look more closely at operational issues, specific dignity policies of the organisation or service, how these are implemented, what people who use services have said about dignity issues in surveys, how complaints are dealt with, how the organisation or service learns from its mistakes, how it is rated in relation to dignity by regulators and inspectors and so on.

Commissioning for Dignity

The Department of Health places considerable emphasis on the commissioning role as a shaper of services. Commissioning is central to providing effective health and social care for both children and adults. It is the process by which PCTs and local authorities decide how to spend their money to get the best possible services for local people. If commissioning strategies and the contracts that are made with providers do not capture the priority issues, the services are unlikely to do so either. This means that, to be influential in relation to dignity issues, OSCs will need to get to grips with how local commissioning strategies are developed and how they are reflected in contracts.

- How have people who use services been involved in developing commissioning policies to include dignity issues?
- Is there an outcomes-based approach to commissioning that emphasises outcomes relating to dignity and respect?
- What general evidence is there that commissioners have thought about dignity in commissioning strategies, frameworks, service specifications, individual contracts and in their approach to personalisation of services?
- How have dignity issues been built into health commissioners' Commissioning for Quality and Innovation (CQUIN) schemes?
- How are dignity issues built into contracts for individual commissioned services (for example is dignity built into the accreditation process for home care providers)?
- How are the dignity aspects of contracts monitored in relation to outcomes achieved?
- What action is taken to feed positive and negative experiences into future commissioning strategies?
- How is compliance with dignity policy reported to the Board/Executive/Governing Body and how often?
- Does any member of the commissioning Board/Executive/Governing Body have responsibility for leadership on dignity issues?
- What other dignity champions are there among commissioners?
- What training is provided for commissioners on how to commission for dignity?
- Are PCT and Council policies on commissioning for dignity aligned with each other?
- Is there a "whistle-blowing" policy and evidence that those who raise issues of concern are encouraged and not victimised?



Dignity in care – commissioning

NHS Western Cheshire has embedded the dignity agenda in the Quality Section of the standard NHS contracts with its main providers for acute, community services and mental health services. Providers will be performance managed against these Quality Schedules through annual work plans at formal contract and quality meetings.

These documents encompass a number of components including:

- patient/service user experience – how will the journey feel for patients/service users and families/carers?
- personalised care – will the service meet an individual's need?

Specific mention is made of providers ensuring services are delivered in line with the Dignity in Care Campaign, and ensuring all best practice guidance is used eg Age Concern's *Hungry to be Heard*. However these documents go further, for example: there are sections on Personalised Care and Equality and Diversity. To highlight the importance given to the dignity agenda NHS Western Cheshire has stipulated compliance (demonstrated through audit) against providers' Privacy and Dignity Policy.

NHS Western Cheshire has used the new national Commissioning for Quality and Innovation (CQUIN) scheme, which links payments to providing high quality care, to select areas which contribute to the dignity agenda, such as focusing on improved care at the end of life by all providers.

Is your review about an organisation or institution or a particular service?

In any of these cases, you will want to be aware in what **settings** care is provided, as these may determine which aspects of dignity are paramount in your review.

- For example, if you are looking at a hospital setting, you may want to prioritise issues such as modesty and privacy
- whereas if you are looking at care provided in people's homes, your focus may be on issues such as communication and autonomy (for example, do care providers respect the service user's wishes about how things are done in their own home or do they insist on doing it "their way"?).

Dignity in care – recently bereaved people

Winner of the South West Peoples Award for Dignity 2009, the Viewing Rooms Project at North Bristol NHS Trust aims to improve the experience of the hospital's recently bereaved service users, increasing their privacy, dignity and access by creating a warm, welcoming environment where the grieving process is less distressing.

Twenty recently bereaved families were given disposable cameras and asked to capture their experience at the hospital. The resulting images showed that more thought needed to be given to the perspective of bereaved people.

A Viewing Room Steering Group was established which included patient panel members, carers, local funeral directors and next of kin who had used the viewing rooms. Over 200 people gave their ideas on redevelopment of the rooms. SANDS, a support group for parents, was also involved to ensure that the new design met the needs of parents and siblings. Both mortuary viewing rooms were refurbished in 2009, following the new designs and were due to open at the end of October 2009.

What type of care are you investigating, who is providing it and for whom?

Being clear about this from the beginning will help you decide on which aspects of dignity you want to focus. For example:

- you would want to ask different questions about an incontinence service largely used by older people from the questions you would ask about a mental health service for people of all ages
- if you are looking at a service provided to a very multi-ethnic community, you will want to ensure that you understand the different concepts of dignity that may prevail in different groups and that cultural and religious differences are respected
- similarly, if you are looking at dignity issues for young adults you will need to understand what matters to the young people themselves – eg, being with other young people may be more important to them than being with people of the same sex
- if the organisation you are looking at provides meals and helps people to eat, you will have a whole set of questions around dignity and food which would probably not be relevant to, say, a sexual health service for younger people, where you would want to focus on issues such as confidentiality.
- if you are looking at nursing care which involves helping people with normally private bodily functions, you may want to focus on different aspects of dignity than if you are looking at the role of medical consultants, where communication may be the most important aspect of dignity.

All of the above examples indicate that scrutineers should be clear from the beginning which aspects of dignity they want to look at. A number of different policy documents and “dignity audit tools” may be helpful to you in thinking through the issues at the scoping stage of your review. Many of these relate to care of older people, but there is an increasing awareness of dignity issues for other groups, such as those with learning disabilities. Many of these are listed in the further information section at the end of this guide. Being clear about the aspects of dignity that you want to investigate will help you put the **right questions** to the **right people** and make the **right recommendations**.

Service areas in which respect for dignity may be particularly important and challenging

As this guide makes clear, dignity is important in all aspects of health and social care. However, there are some areas, groups and stages in people’s lives or their “care pathway” where respect for people’s dignity may be more at risk, or where it has proved precarious in the past. By paying particular attention to these areas and stages, OSCs may be able to add extra value to their scrutiny work.

- Transitions **within** services (eg the number of ward moves an individual experiences within an acute hospital; consistency in assistance for people receiving supported living; the overuse of transitory agency staff)
- Transition **between** different NHS services or between different social care services, eg when people are coming out of hospital and moving from acute to intermediate care, have any aids or equipment they may need been arranged, has their medication and any information and help they may need to take it been sorted out? Or when young people, such as young people with learning disabilities, are moving from children’s services to adult services, how much have they been involved in decisions about their care?

- Transition **between health and social care**, eg when people are discharged to home from hospital and needing social care services
- Transition **between statutory and voluntary services**, eg transition from hospital to the Red Cross Home from Hospital service
- Services for people with dementia and their carers
- Services for people with learning disabilities
- Services for people who are receiving both health and social care
- Care at the end of people's lives and bereavement services.

Dignity in care – people at the end of life

Winner of the National 2009 Peoples Award for Dignity in Care, chef Chris Took has transformed meal times for terminally-ill patients at the Hospice of St Francis in Berkhamsted.

Chris tailors his menus for each individual patient, taking note of dietary requirements and people's preferences. When he joined the hospice eight years ago, he made the unconventional move of leaving the kitchen to chat to patients and families about their meals. Since then Chris has trained teams of volunteers who serve the meals. They have learned the importance of good presentation, knowing each patient's preferences and double-checking each tray before it goes out. They know, for example, that metal spoons should not be given to cancer patients as chemotherapy gives them an unpleasant taste.

Chris also prepares meals for family celebrations - a home-cooked meal for family members and a fruit smoothie for the patient if they can no longer manage solid food.

Clinical staff recognise the important role he plays in improving the quality of patients' lives and marvel at how he can get a reluctant patient to eat again. For the patients, knowing that food has been prepared with such care and close attention to detail brings peace of mind.

Dignity in care – people with learning disabilities

1. Adults with learning disabilities across Derbyshire are being provided with 'Health Files'. These are personal records that they have about their own health. They are to help with communication, appointments and information. They give the person more control of their own health information and help health professionals to give information to the patient, rather than to the carer.

2. Northamptonshire County Council won the 2008 East Midlands Health and Social Care dignity award for its work with a number of people with a learning disability who wanted to have an ordinary life, using the *In Control* approach to enable them to self-direct their support. The Council's approach is to move away from thinking of people as clients, service users or as having 'special needs'. Instead it is endeavouring to work with them as citizens who have the right to many of the things that most citizens take for granted, such as: making decisions, deciding the 'direction' of their life, a home, money, what kind of support they have, and involvement in their neighbourhood / community.

During 2006/07 an 'ordinary living project' had enabled 22 people with a learning disability to move into their own homes with support and made a 19% reduction in the number of admissions to residential care. Self-directed support - bringing together a person's own plan with a personal budget to fund it - is the tool that has been used to make this happen.

4

Scrutiny - gathering and assessing evidence

Measuring dignity – sources of local information

The Care Quality Commission (CQC) uses the following core standard (number 13 of 24) against which it assesses both commissioners and providers of **healthcare**:

Core standard 13: *Healthcare organisations have systems in place to ensure that staff treat patients their relatives and carers with dignity and respect.*

Service inspections of **adult social care** use the CQC Adult Social Care Outcomes Framework. Within this Framework, seven “outcome areas” are defined:

Outcome area 7: *Maintaining Personal Dignity and Respect.*

In grading the seven outcomes for adult social care 2008-09, an authority cannot obtain a higher overall judgement on how well it is delivering outcomes than the classification “performing adequately” if services are graded as performing poorly at outcome 7. Nor can it obtain the classification “performing excellently” unless the grading for outcome 7 is at least “performing well”. In short there is a key threshold applied to the outcome on dignity and respect.

CQC assessments for your local institutions commissioning and providing health and social care are available on the CQC website for comparison (your own social services department and PCT should also be able to provide you with copies of these).

NHS Choices (www.nhs.uk) in the section “Find and choose services” can also be a useful source of anecdotal evidence on individual NHS trusts. People who have used services can make their own comments on this website and they are listed by Hospitals, GPs, Dentists and Other services.

The website Patient Opinion (www.patientopinion.org.uk) also contains individuals’ views in their own words about treatment they have received. It is searchable by postcode and NHS institution.

Measuring dignity – using indicators

Measuring dignity is ultimately about assessing people’s experience and can involve some very personal feelings – this is notoriously difficult to capture in the form of objective evidence and statistical reporting. However, there has been considerable recent work to develop ways of assessing the factors that will lead to the desired outcome of an experience of being treated with dignity and respect. This has led to a number of “dignity indicators” being developed for different settings, different kinds of care and different groups of people, many of which have been gathered together in the “dignity audit tools” referred to above. (Details of all of these are given in the section on further information, see page 26.)

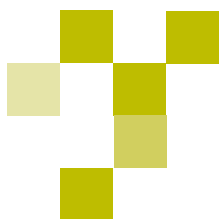
For example, on behalf of Help the Aged, the Picker Institute produced a report on measuring dignity in care for older people. This develops dignity indicators under four main themes: **choice, control, staff attitudes** and **facilities**. These are used to assess services against Help the Aged’s “dignity domains”, developed through consultation with older people:

autonomy – eg involvement in decision-making about care

communication – eg forms of address, access to translation, telling people in advance when changes are being made to their domiciliary care

end-of-life care – eg choice of where to die and who to be with

eating and nutrition – eg appropriate and sensitive assistance to eat when required



pain – eg staff ask about/acknowledge pain

personal hygiene – eg sufficient, clean and suitable washing/toilet facilities

practical assistance/personal care – eg respect for personal possessions, ensuring consistency in the staff providing personal care – it is not appropriate for a different person to arrive every day to give someone a shower

privacy – eg permission sought before students are present during examination or when a carer enters someone's home, bedroom or bathroom (including residential care homes, which are also people's homes)

social inclusion – eg contact maintained with friends and family

The Royal College of Nursing (RCN) has concluded that providing dignity in care centres on three integral aspects: **respect**, **compassion** and **sensitivity**. Translating these hard-to-measure characteristics into practical action, the RCN believes that this results in indicators such as the following.

- Facilities such as toilets should be well maintained and cleaned regularly
- Curtains between beds should close properly to offer some measure of privacy
- Toilet doors should be closed when in use
- Bays in wards should be single-sex (this is controversial as patient surveys indicate that patients don't always see single-sex bays amounting to single sex accommodation)
- Gowns should be designed and made in a way that allows them to be fastened properly to avoid accidental exposure
- Privacy should be provided for private conversations, intimate care and personal activities, such as going to the toilet.

Different indicators will of course apply for people living in their own homes, including care homes. Many people whose dignity has not been respected say that it's "the little things" that make a difference. Of course, the issues above aren't really "little things" if they take away people's dignity. The fact that they may not always be considered important by those in charge, doesn't mean that this is right.

Dignity in care – hospital in-patients

The Dignity and Respect Action Group at Southend University Hospital brings together staff, patients and volunteers to share stories and take forward plans to improve the experience of patients. The group was set up by tutors from the Hospital and Anglia Ruskin University along with staff who received specially designed dignity and respect training. They decided to set aside time, away from their day-to-day clinical duties, to explore and develop their ideas further.

Since forming in 2004, the group's approach has led to a pioneering range of innovations in the hospital. These include: a complete overhaul of the nightwear and gowns used in the hospital, introducing more dignified designs; rain-proof covers for wheelchair users when travelling between hospital buildings; the provision of quiet-closing bins in patient areas to cut down noise levels; and the introduction of 'Privacy Pegs' for securing bed curtains together to make staff more aware that they are entering a patient's personal space.

A website is now being developed to help spread the word and promote the group's ethos of respect and dignity for all.

The NHS Institute for Innovation and Improvement (www.institute.nhs.uk) has produced a number of training and development modules under the general heading of “The Productive X”. (eg The Productive Ward, The Productive Community Hospital, The Productive Mental Health Ward, Productive Community Services). These are all designed to improve practice with a strong emphasis on the experience of people using health services, and include many issues relating to dignity. They may be helpful for OSCs in developing a set of measures against which they can make assessments of dignity and respect as part of a scrutiny review.

Listening to personal stories

We all know that the things on the above lists could all be in place and could certainly afford a measure of dignity but without the right personal qualities, such as compassion, that are needed to complete the picture. This is why OSCs need to use a range of styles and settings to obtain a rounded picture. Many OSCs are becoming more adventurous in using a mixture of formal and informal methods, such as focus groups, visits and workshops. Capturing people’s direct experiences in their own words and hearing their “stories” is vital in assessing dignity. It is something that OSCs are uniquely suited to – many OSCs have found that the scrutiny process, in giving people an opportunity to tell their own stories, has itself contributed to validating and making them feel better about their experiences, even negative ones. And listening to stories eg by talking to Dignity Champions and LINks members is a way for OSCs both to engage with people’s experiences, to get a sense of how the system is working, and to “triangulate” the evidence they receive – that is, to test out evidence from different sources.

Dignity in care - dignity in a word

Warrington Borough Council is the only council to have achieved Beacon Status for Dignity in Care in 2008/09. The Council recognises that, alongside other authorities, it is on a journey to improve service user experience of care, addressing all aspects of dignity and respect. The Council’s initiative, “Dignity makes sense” asks people simply to use their five senses to identify and respond to problems.

It has created a DIGNITY acronym to sum up the approach it believes will capture the most important factors:

Developing capacity – maximising the contribution of partners across all sectors

Involving – supporting people who use services and their carers to be involved in service development

Giving a lead – setting high standards for all health and social care services

Noting detail – attention to detail makes a real difference

Individualisation – recognising and treating each person as an individual with real choices about services

Training – dignity is an ongoing journey and we must continue to learn more

Your story... – always being alert to people’s real experiences of health and social care services

© Warrington Borough Council

Listening to people's personal stories is actually also a way of helping them retain dignity, as it shows respect for them as a whole person with a lifetime of experience, reminding both the carer and the person cared for that there is much more to the individual than is visible at the moment of care. Some organisations have developed programmes of work based on the idea of Life Stories, as part of their approach to dignity.

Dignity in care – life story work with older people

The Oldham Life Story Steering Group (including Age Concern, Oldham Council Social Services, Pennine Care, Oldham PCT and the Carers Forum) have developed a joint approach to Life Story work becoming integral to the care planning process for older people and their carers. The award-winning work was developed by a former carer who started by preparing an account of his wife's life for the staff in the residential home she was moving to. Life Story work is used in different settings in Oldham, including in Urdu with older Pakistani women.

Dignity in care – an active role for care home residents

Kim Hirst, Care Manager for Highroyd Residential Home in Huddersfield decided to invite a resident for two years, Alison M, to help interview prospective new staff. With Kim's help, Alison put together questions from the residents' point of view for interviewing new staff members. Alison recently played an active part in interviewing candidates for night care.

Alison commented, "I was very nervous at first but soon got used to it, I read my questions out and listened to the answers. [The successful candidate] stood out and is very nice."

Manager Kim Hirst said, "This home is for our residents and at the end of the day carers are very important and the residents should have a say in who is going to look after them".

Leeds City Council has recently adopted an initiative pioneered by Warrington, focusing on dignity in the commissioning of external services. Leeds developed new performance indicators for external contracts using the ten dignity standards of the Dignity Challenge, including intolerance of abuse, maintaining independence, listening to people's wants and needs, maintaining privacy and alleviating loneliness.

It can be seen from the above examples that different indicators will be more relevant to some settings, services, groups of people and care givers than to others. Most of the well-developed indicators to date relate to the care of older people, but many of these apply more generally. OSCs may either wish to use or adapt a tried and tested set of indicators for a particular review on which to base their questions, or may wish to develop their own indicators, based on their discussions at the scoping stage. What is important is that Members should reach their own understanding in relation to any group whose care they are reviewing of what it means to treat this group of people with dignity and respect, bearing in mind that the answers may be different for different groups of people.



Dignity in care – older people

Leeds won the National Dignity in Care Award 2008 for its work on the Dignity in Care campaign. Its work was started when the Leeds Older People's Forum prioritised "being treated with respect and dignity" as one of their most important issues. A Scrutiny Board inquiry into dignity in care has helped make it a key organisational priority across the system. For example, older people were involved in setting criteria for the allocation of capital grants to care homes and in the selection process. Other changes that have taken place include:

- more small lounges in care homes so that people can talk to visitors in private
- improving garden areas or creating better ones
- small kitchens where residents can prepare their own meals when they want to
- better training for staff
- a range of posters and postcards to raise awareness, including quotations from older people about their expectations of being treated with dignity and respect
- a number of dignity audit tools, including a tool for evaluating dignity and respect in care homes, and another for mental health settings (see section on further information below).

Who should you talk to and what should you ask them?

Members of OSCs and officers supporting them are well aware that the people who provide evidence and information for a particular review can make a big difference to its success. The following is a list of people who might assist OSCs in a review involving dignity issues and the sort of information they could help to provide.

Decision makers/policy makers (including members of governing bodies, non-executive directors and councillors)

Do they understand issues of dignity and respect and what they mean to the people who use their services? How do they keep informed of service users' views? Can they show that they take account of dignity issues in developing policies and making decisions? How do they show leadership and act as dignity champions?

Commissioners

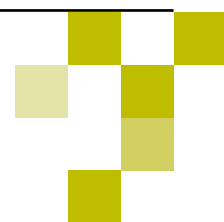
What is their own understanding of dignity and respect? How do they systematically build dignity issues into contracts? What measures of dignity do they use and how do they assess compliance? How do they collect evidence of service users' experiences? How do they ensure that those experiences influence future commissioning?

Service providers (managers)

How do they show leadership on dignity issues? What policies do they have? What measures of dignity do they use? How do they monitor them? How do they collect evidence of service users' experience? What induction and training of staff do they provide? How do they learn from mistakes and complaints?

Service providers (frontline staff)

How do frontline staff themselves understand dignity and respect? Do they know about, understand and systematically implement relevant policies? How do they translate these into their own professional practice and relationships with the people they care for? Do contact centre or reception staff reflect the culture of the organisation and its approach to dignity?



Service users

What is their understanding of what it means to be treated with dignity and respect? Do they have personal experiences that reflect how care is commissioned in the area, or on organisations and services as a whole? Have they been included in developing policies on dignity and respect? In talking to individual service users and hearing their stories, as with other scrutiny reviews, it will be important to have a strategy for testing out whether one individual's experience reflects the experience of others, or is unique in terms of the quality of care they have received.

Carers (for example, carers of people with dementia who may not be able to speak for themselves, young carers of parents with disabilities)

Carers, both young and old will have their own perspective on the kind of care the person they care for has been receiving. What can they tell you about how the people they care for are treated? Are they themselves treated respectfully by health and social care professionals? Have they felt able and been encouraged to raise issues and/or complaints without fear of retribution for themselves or the person they care for?

It will be important to keep a clear distinction between service users and carers. For example, it hardly needs saying that hearing the views of a service user's parent, child or spouse is not the same thing as hearing the views of the service user herself/himself.

Local Dignity Champions

Can they help you gain an overview of what is happening generally in relation to dignity in an area and how the issue is being promoted and received?

Patients', service users' and carers' organisations (such as LINks and organisations for particular groups, eg older people, black and minority ethnic people, young people)

Do they monitor issues of dignity and respect? What evidence do they have of service users' and carers' experiences? If they have raised dignity issues with commissioners and providers, what response have they had?

Professional organisations, national voluntary sector organisations and researchers

How have they developed their measures and indicators? What advice can they give to the OSC on how it should be testing organisations/services in relation to dignity? Consulting such organisations may be particularly important for reviews not restricted to dignity for older people, as there is much less literature available in relation to other age groups. OSCs may also be able to enlist the help of third sector organisations and/or universities in gathering the views of people using services, eg through focus groups or surveys.

Representatives of partnerships (such as the Health and Well-being Partnership Boards that are part of Local Strategic Partnerships)

The Dignity in Care campaign has shown that strong local leadership and effective partnership working is essential to raising the profile of the issue and ensuring that all local commissioners and providers of health and social care are consistently promoting dignity. Have issues of dignity and respect been discussed by the Health and Well-being Partnership Board or other partnership forums? Are any members of these forums Dignity Champions? Is there a common understanding of dignity (possibly embodied in a code of practice)? Are any performance indicators relating to dignity regularly monitored by partnerships, for example in the Local Area Agreement?

Dignity in care – people with dementia

1. Working in partnership, Cambridgeshire Libraries and “Dementia Positive” have developed a project, Countering Stigma in Dementia Through Creativity. The project employs a poet with extensive experience of working with people with dementia, enabling them to express themselves about their condition and life generally, and to shape their insights in poetic form. Their work will be disseminated through readings, posters and a book. Training will be offered to librarians, care staff and medical practitioners to help them to encourage and value creativity beyond the end of the project. Carers will be involved and encouraged to use library facilities. The results of the project will be shared across the region, with media involvement, to promote the Dignity in Care campaign.

2. Meri Yaadain (meaning My Memories) is a nationally recognised award winning initiative to break down misconceptions about dementia and provide information and support to individuals and carers in the South Asian communities. Its success has led to a long-term initiative to raise awareness of dementia amongst the older South Asian communities in Bradford. See a short video and more information at:

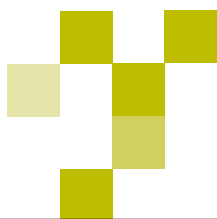
http://www.merियाadain.co.uk/about_meri_yaadain_project.html

Dignity in care – people with learning disabilities

The Warrington Checking Out Project supports tenants with learning disabilities to check out, comment on and influence the quality of supported living provision. Using the experiences, views and ideas of people receiving support the project promotes their rights as tenants to receive a quality service that recognises individuality and choice, enabling individuals to live the life they want in the way they want.

The project is a joint venture between Warrington Borough Council and Changingtogether, an independent consultancy.

The project has developed an information and resource pack which will be published nationally as a legacy of the Dignity in Care beacon award 2008-09.





After carrying out scrutiny work for a number of years now, OSCs are familiar with the importance of laying out **evidence, findings** and clear, focused **recommendations**, making clear to which organisation individual recommendations are addressed. With a concept as complex, shifting and individual as dignity, it is particularly important to be clear about what definitions you have been using, what aspects of dignity you were focusing on, what questions you were seeking to answer, what you found out, from whom, what you are recommending, to whom and why.

OSCs will want to make recommendations on dignity issues to a number of bodies, depending on the aspects they have been considering in a scrutiny review. This could include the Council's Executive, the PCT and/or NHS Trusts, providers of social care, voluntary organisations etc. It is worth remembering also, that OSCs may make recommendations to their fellow councillors. This was done at Lincolnshire County Council when a scrutiny task group looked at the Member role in Adult Social Services. The task group identified dignity as an important issue where Members themselves could add value, for example in their regular visits to care homes. As a result of this, a series of workshops was organised for Members to discuss the issues and the actions they themselves could take in relation to dignity and respect for their residents.

In addition to formal reports and recommendations, OSCs might consider other kinds of outputs to support their findings. Given the importance of personal experience in relation to dignity, a review might produce case studies and "stories" that reflect on individual experiences discovered by the OSC. Of course, if general conclusions are drawn from an individual experience, they will need to be supported by other evidence. Nonetheless, reflecting on one person's experience can lead to discoveries about a whole system or organisation and such reflections can bring a human touch to what might otherwise be a rather dry report. They can also be used to illustrate conclusions about an issue as the culture of an organisation which can be difficult to pin down without examples.

Other potential outputs could include examples of good practice and improvement tools such as the Leeds dignity audit tool which was developed as the result of a scrutiny review.

Because dignity is such a personal issue, and because OSCs are likely to have heard some very personal experiences in the course of a review involving dignity issues, it will be particularly important to give **feedback** to people who have given their time to provide evidence and to plan **follow-up** to assess the impact of the review and its recommendations. As OSC Members will be aware, the knowledge that you will be returning to your recommendations and asking questions about their implementation can be a very effective driver of concerted action.

Scrutiny Reviews Prioritising Dignity Issues

LONDON BOROUGH OF HACKNEY: DIGNITY IN CARE (OLDER PEOPLE SERVICES) (2008)

Outcomes: Dignity Code included in Floating Support service contract for older people; plans to vary existing contract to include Dignity Code; Code included in all training for staff who provide services; PCT has attached Code as an appendix to its contracts; monthly report to PCT Board of Directors; Code adopted by all NHS trusts.

Download report

HALTON BOROUGH COUNCIL: SAFEGUARDING VULNERABLE ADULTS (2008)

Outcomes: development of a protocol on safeguarding vulnerable adults between Halton Borough Council and local NHS trusts; training for elected Members on safeguarding issues; setting up of a Dignity in Care Board to monitor dignity issues.

Download report

LEEDS CITY COUNCIL: DIGNITY IN CARE FOR OLDER PEOPLE (2007)

Outcomes: a joint action plan between the Council and the PCT to meet the OSC's recommendations – included publicity materials; improved food and help with eating in hospitals; dignity performance measures in contracts; new safeguarding procedures and dignity workstreams in NHS trusts; a dignity audit tool developed.

Copy of responses to recommendations

LINCOLNSHIRE COUNTY COUNCIL: MEMBER ROLE IN ADULT SOCIAL CARE (2009)

Outcomes: dignity identified as important area for Members to add value, series of workshops arranged for Members on Dignity and Choice, Council signed up to Dignity in Care Campaign, monthly newsletter for Members on social care.

Download report

MIDDLESBROUGH COUNCIL: DIGNITY IN CARE FOR OLDER PEOPLE (2008)

Outcomes: Inclusion of questions on dignity and respect in annual surveys of people receiving home care and residential care.

Copy of the report

NORTH EAST LINCOLNSHIRE DIGNITY IN CARE SELECT COMMITTEE (2008)

Outcomes: meetings between OSC Chair and Chair of NE Lincs Care Trust Plus; OSC recommendations incorporated into wider action plan by care trust.

Copy of the report



Further information

General publications referenced in this guide

Audit Commission (2004), **Older people - independence and well-being: the challenge for public services**. London, Audit Commission.

CSIP, Care Services Improvement Partnership (2005), **Everybody's Business: integrated mental health services for older adults - a service development guide**. Department of Health.

DH (2004a), **Seeking consent: working with older people**. London, Department of Health.

DH (2005a). **Independence, well-being and choice: Our vision for the future of social care for adults in England**. London, Department of Health.

DH (2006f). **Our health, our care, our say: a new direction for community services**. London, The Stationery Office, HM Government.

DH (2003c). **Essence of Care: patient-focused benchmarks for clinical governance**. NHS Modernisation Agency.

Help the Aged & Royal College Of Nursing (2000). **Dignity on the ward: improving the experience of acute hospital care for older people with dementia or confusion - a pocket guide for hospital staff**. London, Help the Aged

Horton, R. (2004) **'Rediscovering human dignity'**. The Lancet, 364, 1081-1085.

Housing Learning & Improvement Network, Care Services Improvement Partnership (2006) **Dignity in housing**.

SEU/ODPM (2006). **A sure start to later life: ending inequalities for older people: final report**, London, Social Exclusion Unit/Office of the Deputy Prime Minister.

Wanless, D. (2006). **Securing good care for older people. Taking a long-term view**. London, King's Fund.

Useful websites

Dignity indicators

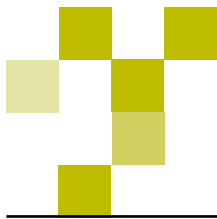
Dignity Indicator – NHS Inpatient Survey results for 2007/8 and 2008/9 by Trust – contains data on the percent of patients in each NHS Trust who felt they were treated with dignity and respect while in hospital.

Dignity Map for Older People – Department of Health document and web resource which looks at indicators for different aspects of dignity. Designed to relate to older people, but also useful more generally.

Magee, H., Parsons, S., and Askham, J., *Measuring Dignity in Care for Older People*, Picker Institute for Help the Aged, 2008.

Leeds Dignity Challenge Audit Tool - Mental Health Settings.

Leeds Older People's Strategic Partnership and Age Concern Leeds, **Privacy and Dignity Care Home Evaluation Tool**



Central and Eastern Cheshire PCT and Age Concern Cheshire, **Dignity Assessment Tool** Healthcare Commission report, **Caring for Dignity: a national report on dignity in care for older people while in hospital**, contains a number of recommendations which could be used as benchmarks against which to evaluate NHS Trusts.

Woolhead G, Calnan M, Dieppe P, Tadd W (2004), *Dignity in older age: what do older people in the United Kingdom think? Age and Ageing*. 2004 Mar; 33(2): p165-70

Further reading

Much more information about the Dignity in Care Campaign, the Dignity Challenge and Dignity Champions can be found on the Department of Health Website at:

www.dignityincare.org.uk

The Dignity Champions database can be found from the Dignity in Care websites or by going to: <http://www.dhcarenetworks.org.uk/dignityincare/BecomingADignityChampion>

The Royal College of Nursing dignity campaign is described on the RCN's website which has a number of downloadable documents on dignity issues, examples of good practice, practical toolkits etc: <http://www.rcn.org.uk/newsevents/campaigns/dignity>

A Dignified Revolution is a group of individuals, the majority of whom are nurses, who want to improve the care of older people in hospital. They have their own website with guides, case studies and other useful information: <http://dignifiedrevolution.org.uk>

The Social Care Institute for Excellence has an extensive web-based resource on dignity in care at: <http://www.scie.org.uk/publications/guides/guide15/index.asp>

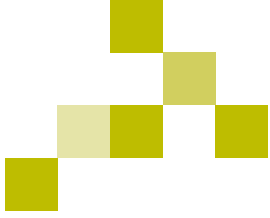
Warrington Borough Council, as Beacon Council for Dignity in Care 2008-09, has set up a website to act as a portal of good practice documents, links to useful articles, events and websites: <http://www.warrington.gov.uk/beacon/>

Bradford Dementia Group have produced a powerful and thought provoking DVD about caring respectfully for people with dementia. More information at: <http://www.exmemoriafilm.co.uk/>

Barnsley Primary Care Trust and Barnsley Metropolitan Borough Council have produced *Focus on Dignity in Health and Social Care*, a self-directed learning tool for those working with people with learning disabilities. This was written by Joanne Brown and Katrina Latham and is obtainable from Barnsley Integrated Learning Disability Service (BILDS).

There are many sources of information on how "life story" work is used with a number of groups of people using health and social care services, such as children people with learning disabilities, older people on medical wards and with older people who have dementia. It can help challenge ageist attitudes and assumptions, provide an approach to people as individuals, assist in transitions between different care environments, and help to develop improved relationships between care staff and family carers. The website of the Social Care Institute for Excellence has a description of life story work with older people at: http://www.scie.org.uk/publications/elearning/mentalhealth/mh10/resource/html/object10/object10_4.htm

The Life Story Network is a community of interest developed to create further discussion and sharing of positive practice in the use of life stories: <http://www.lifestorynetwork.org.uk/>



The Equality and Human Rights Commission has produced a report, *From safety net to springboard*, on a new approach to care and support based on equality and human rights: http://www.equalityhumanrights.com/uploaded_files/safetynet_springboard.pdf

The Institute of Public Care has developed a “roadmap” on good practice in outcomes-based commissioning for ADASS North West, NHS North West, North West Joint Improvement Partnership and the North West Regional Director of Public Health: <http://www.northwestroadmap.org.uk>

The NHS Institute for Innovation and Improvement has produced a number of modules in the Productive Series which supports NHS teams to redesign and streamline the way they manage and work – intended to release more staff time for patients: http://www.institute.nhs.uk/quality_and_value/productivity_series/the_productive_series.html

High quality services for carers rely on high quality commissioning. With this in mind, the Department of Health has funded a consortium to produce a guide for commissioners that is available on the IDEA website: www.idea.gov.uk/idk/core/page.do?pagelid=13255730

The Centre for Public Scrutiny has an extensive, searchable on-line library of scrutiny reviews: <http://www.cfps.org.uk/scrutiny-exchange/library/>

Abuse

“**No secrets**” is the Department of Health guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse: <http://www.elderabuse.org.uk/Useful%20downloads/No%20Secrets%20etc/No%20Secrets.pdf>

The Social Care Institute for Excellence practice guidance on making referrals to the Protection of Vulnerable Adults (POVA) gives information on the “warning signs” of abuse: <http://www.scie.org.uk/publications/guides/guide12/deciding/deciding4.asp>

Action on Elder Abuse provides guidance on how to report suspected abuse and runs a confidential helpline: www.elderabuse.org.uk (0808 808 8141).

Appendix 1

Legislation and policy background

Legislation

The **Human Rights Act** came into force on 2 October 2000. It gives individuals a number of rights, including rights which impact directly on health and social care, such as the right to life, the right not to be subjected to inhuman or degrading treatment, and the right to family life. The Human Rights Act means all public authorities must ensure that everything they do is compatible with the European Convention on Human Rights (based on the Universal Declaration).

From 1st December 2008, the protection of the Human Rights Act was extended to people living in publicly funded accommodation with nursing or personal care. Under section 145 of the Health and Social Care Act 2008 providers of accommodation with care will be treated as exercising a function of a public nature. This means that people using these publicly funded care services will now be protected by the Human Rights Act.

Anti-discrimination legislation (sometimes known as equalities legislation) is designed to eliminate unjustifiable discrimination on legally specific grounds, including disability, race, religion, sexuality and gender legislation. The Department of Health is currently conducting a consultation on eliminating unjustifiable age discrimination. The equalities legislation is constantly evolving, as society recognises new areas of inequality, and over the last 30 years a number of laws have been passed in response to changing public perceptions and the development of human rights law.

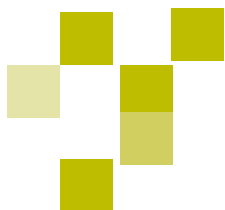
Anti-discriminatory practice is fundamental to the ethical basis of care provision, and equalities legislation is critical to the protection of service users' dignity. It imposes particular responsibilities on public bodies and service providers to avoid stereotyping and to respect service users' diverse needs and cultural diversity. Providers of health and social care also have equivalent responsibilities to their employees.

The legislation is designed to promote the dignity of citizens by ensuring that they are treated with respect.

The **Mental Capacity Act 2005** (MCA) which came into force on 1 October 2007, provides a statutory framework to protect and empower adults who may lack capacity (ability) to make all or some decisions about their lives. The principles set out in the Act promote the human rights and dignity of people who may lack capacity, because they enshrine respect for individual autonomy and make it clear that we should always presume that a person has the capacity to make decisions unless it is established otherwise.

The **Mental Health Act 2007** which amends the 1983 Mental Health Act introduced the 'Deprivation of Liberty' or 'Bournewood' safeguards. These protect against illegitimate deprivation of liberty for people who do not have the capacity to consent to arrangements made for their care that would deprive them of liberty. The Mental Health Act also enhances the human rights and dignity of people who have a mental disorder, including requirements to respect patients' past and present wishes and feelings.

The **Safeguarding Vulnerable Groups Act 2006** sets out a new scheme which aims to help avoid harm, or risk of harm, to children and vulnerable adults by preventing people who are deemed unsuitable to work with children and vulnerable adults from gaining access to them through their work. The potential for enhancing the dignity of people using services is that the Act allows for more effective checking of staff, including workers in healthcare settings who are not covered under the Protection of Vulnerable Adults (POVA) List. People receiving direct payments or individual budgets are also able to access the scheme to make checks.



Information held by public bodies is governed by the requirements of the **Data Protection Act 1998** (DPA) which requires data controllers who process personal information to comply with a range of data protection principles. In essence, this Act supports the importance of sharing information with people using services. There are very few exceptions to this. Enhancing the dignity of people using services demands that practitioners pay attention to confidentiality. There are some limits on confidentiality and these apply where there is a risk of harm to other people.

The **Freedom of Information Act 2000** (FoIA) provides statutory rights for members of the public requesting information. The FoIA imposes a duty on public bodies to adopt schemes for the publication of information which must be approved by the Information Commissioner.

In general, information legislation protects the human rights, privacy and dignity of service users by protecting confidentiality and enabling service users in certain circumstances to have access to the information that is held about them.

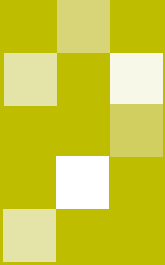
National and international policy

The Department of Health's Green Paper, '[Independence, well-being and choice](#)' (2005a) and subsequent White Paper, '[Our health, our care, our say](#)' (2006f), are set around seven key outcomes identified by people who use services, one of which is personal dignity and respect. The Commission for Social Care Inspection (CSCI) incorporated these into its assessment framework, 'A new outcomes framework for performance assessment of adult social care' (2006) and the issue of dignity is now being taken up by the CSCI's successor body, the [Care Quality Commission](#) in relation to both health and social care. The Department of Health's [National Service Framework for Older People](#) (2001) also supports a 'culture change so that all older people and their carers are always treated with respect, dignity and fairness', and its '[Essence of Care: Patient-focused benchmarking for health care practitioners](#)' (2003c) offers a series of benchmarks for practice on privacy and dignity. Lord Darzi's review of the NHS, '**High Quality Care for All**' puts quality at the heart of all that the NHS does; and the new **NHS Constitution** gives people the right to be treated with dignity and respect. Improving the experience of individuals is a key aspect of quality. And whether people are treated with dignity and respect has a huge impact on their experience of using services and is therefore an important contributor to quality.

Putting People First, sets out a vision for transforming social care, enabling a social care system that 'provides care equally for all, whilst enabling people to retain their independence, control and dignity'.

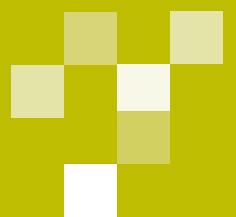
Similar themes appear in documents by a range of agencies. They deal with all services for older people (Audit Commission, 2004) housing and housing-related support (the Housing Learning and Improvement Network, 2006) mental health services (CSIP, 2005), consent to treatment: standards in care homes (DH, 2004a), social exclusion (Social Exclusion Unit / ODPM, 2006) and so on. Voluntary organisations have based campaigns around the idea of dignity in care (Help The Aged and Royal College of Nursing, 2000), and the Wanless Social Care Review (Wanless, 2006) uses the idea of dignity as one factor explaining the relative fairness of different funding systems. Codes of conduct for health and social care practitioners aim to preserve dignity.

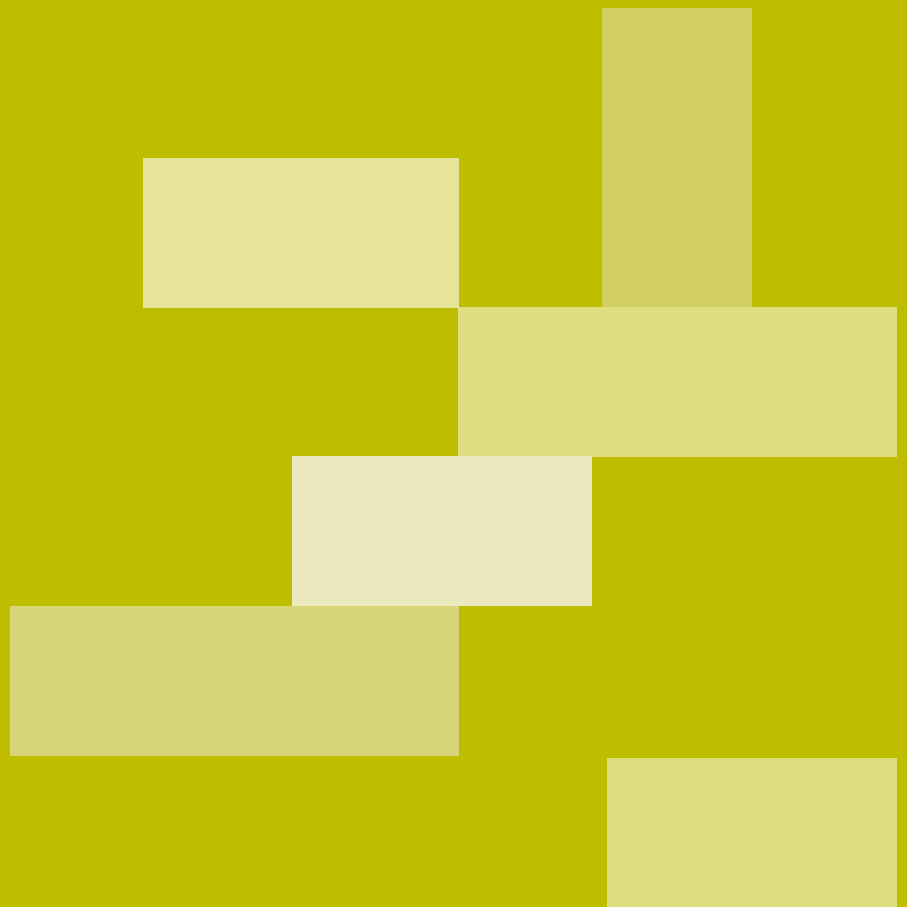
In the international field, the **World Health Organisation** has called for healthcare systems which promote dignity: "The standard equation of ideas used by international agencies is well known: Respect for Persons = Autonomy + Confidentiality + Dignity" (Horton, 2004).



The Centre for Public Scrutiny

The Centre for Public Scrutiny promotes the value of scrutiny in modern and effective government, not only to hold executives to account but also to create a constructive dialogue between the public and its elected representatives to improve the quality of public services. The Centre received funding from the Department of Health to run a three-year support programme for health, care and wellbeing overview and scrutiny committees of social services authorities as they develop their power to promote the well-being of local communities through effective scrutiny of health and care planning and delivery and wider public health issues.





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