Qualitative impact assessment of the National Dignity in Care Campaign

A desk research report prepared for the Department of Health

July 2009

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1.   Introduction and Objectives

Background

"High quality care should be as safe and effective as possible, with patients treated with compassion, dignity and respect. As well as clinical quality and safety, quality means care that is personal to each individual." Lord Darzi 'High Quality Care for All'

Launched by the Department of Health (DH) in November 2006, the 'Dignity in Care Campaign' aims to end tolerance of indignity in health and social care services by stimulating national debate around dignity in care and inspiring people to take action. The objectives of the campaign are to:

- Deliver a public/staff facing 'Dignity in Care Campaign' aimed at:
    – 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

Since its launch, the Campaign has included a range of activities to promote dignity and respect for patients using care services. In particular it has created a network of more than 9000 'Dignity Champions' to work locally, inspiring and encouraging others to make dignity and respect a priority for care services. The Campaign has also worked to raise awareness via a variety of methods: pod casts, an online website, partnership with the Social Care Institute for Excellence and use of their Care Practice Guide, awards, conferences, a 'Dignity Tour' etc.

There have been many developments and initiatives relating to dignity in care since 2006, for example the DH and Comic Relief launched a ' Research Initiative on Elder Abuse, Neglect and Lack of Dignity in the Institutional Care of Older People' in May 2008.

 Locally, dignity is being prioritised following inclusion in the key National Performance Indicators and the Care Quality Commission (CQC) registration requirements. The regulatory background has also changed, with the Health and Social Care Act 2008 making independent sector care homes directly subject to the Human Rights Act and the creation of the Care Quality Commission (CQC) in April 2009 harmonising the regulatory framework and inspections.

However, the sixth National Inpatient Survey highlights persistent problems in important aspects of care linking to dignity such as help with eating, mixed-sex accommodation, involvement in decisions about care and answering call buttons. There has been progress in dealing with these issues since the beginning of the campaign but persistent problems still exist. Cynthia Bower, CQC Chief Executive, said, "It is a great shame that the NHS has not managed to get a stronger grip on these issues when patients have been highlighting them for

so long. As the regulator, we will be doing more to ensure people's views have more clout" (BBC.co.uk, May 13th 2009).

Desk research objectives

The key objectives of the desk research are to gain insight into the issue of dignity in care and identify and summarise the key reports relating to:

- The key background policy drivers from which the 'Dignity in Care campaign' emerged and within which it is currently operating. This covers national strategies, guidance programmes and initiatives
- National studies to guide and evaluate the 'Dignity in Care campaign'
- Local action by SHA's, PCT's and local councils to develop and evaluate activity relating to 'Dignity in Care' in the NHS and social care.

The review will also help to build an understanding of what else is impacting on the Campaign and shaping it on the ground. The articles outlined below summarise both thinking within governmental and related organisations, by academics and other interested groups on how the overall concept of dignity can be made central to the provision of health and social care. The report also reviews the development of the specific 'Dignity in Care campaign' in terms of its research basis and how it has been developed across health and social care at the local level.

Methodology

A detailed search of the relevant national and local public sector web sites and health and social care journal sites has been carried out to assess policy thinking behind the campaign. and progress in developing and evaluating the campaign on a local basis.

The research aims to identify any Strategic Health Authority (SHA) and Primary Care Trust (PCT) level reports and findings pertinent to embedding dignity in the core of patient care and to assess progress in joint action between health and social care to ensure dignity and respect for older people.

The key sources searched for material include:

- Department of Health and SCIE web sites/ CISP reports
- Healthcare Commission/ Care Quality Commission web sites
- Social care databases – e.g. Intute, Social services abstracts, social care online
- Pubmed database
- Picker Institute

- Royal College of Nursing
- Policy Research Institute on Ageing and Ethnicity
- Joseph Rowntree Foundation
- Community care journals/ Age and Ageing/Quality in Ageing
- Charity web sites e.g. Age Concern/Help the Aged
- SHA and PCT web sites
- Local council Health and Social Care scrutiny committees

2. Overall policy context studies

This section covers academic and government sources in defining the meaning of dignity in care and developing approaches to measurement. Studies have been divided into overall studies defining dignity, the issue of dignity in residential care, policy development and additional reviews from outside sources. It should be noted a number of these articles do have overlapping findings in that they review research findings to date.

2.1 Studies on the overall meaning and importance of Dignity in Care

These studies illustrate the problems existing in both health and social care for older people and the central role of the concept of dignity in developing policies to improve standards of care.

2.1.1. Dignity in the care of older people – a review of the theoretical and empirical literature Ann Gallagher, Sarah Li Paul Wainwright, Ian Rees Jones, and Diana Lee BMC Nursing 2008 7 11

Relevance - This is a valuable review article, which critically examines all published studies relating to dignity from academic sources and the Department of Health and provides valuable guidance for future studies on dignity in care. In general those studies reviewed in detail in this report have not been evaluated separately.

Overall aims

The aim of this paper is to examine the literature relating to dignity and to aid nursing staff particularly to address the following questions:

- What does dignity mean?
- What promotes and diminishes dignity?
- How might dignity be operationalised in the care of older people?

Methodology

The following databases were searched: Assia, BHI, CINAHL, Social Services Abstracts, IBSS, Web of Knowledge Social Sciences Citation Index and Arts & Humanities Citation Index. An analytical approach was adopted to the publications reviewed.

Key Findings
What does dignity mean?

Two helpful theoretical approaches are identified from Nordenfelt[1] and Mann.[2] Nordenfelt distinguishes four concepts of dignity –

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[1]   Nordenfelt L. The varieties of Dignity Health Care Analysis 2004 12 69-89
[2]   Mann J Dignity and Health: The UDHR's Revolutionary First Article Health and Human Rights 1998 3 31-38

- Intrinsic dignity we have as humans
- Dignity of merit
- Dignity of moral stature
- Dignity of personal identity, which can be taken away from people when they are humiliated or treated as objects

Health care professionals are generally expected to treat all patients who come before them, regardless of their moral character or civic status. Aristotelian virtue theory also reminds us of the importance of dignity as a quality of the health care professional. Nurses, by this account, would be expected not only to respect the dignity of patients but also to exhibit dignity in their own character.

'Dignity of identity' is of particular interest to nurses, as it has the potential to give the clearest guidance as to how we should treat other people in practice, so as to preserve their dignity. The importance of dignity of identity provides, for example, a theoretical justification for providing individualised care.

Mann developed a taxonomy of dignity violations
- Not being seen – e.g. nurse avoiding patient attempts at engagement
- Being seen but only as a member of a group
- Injuries to dignity resulting from violations of personal space
- Humiliation

From the review of the literature and interdisciplinary discussions, it would be argued that dignity is fundamentally concerned with claims of worth or value, with behaviour that justifies such claims and with treatment by others that shows appropriate respect: dignity is thus not reducible merely to autonomy or to respect. Further, dignity serves an important function in nursing ethics and is a necessary and appropriate nursing value.

What promotes and diminishes dignity in practice – learning from empirical findings
There are many similarities among the various empirical studies. Findings from the 'Dignity and Older Europeans' study[3] suggests that dignity is a multi faceted concept and supports the significance of: staff behaviour and attitudes; the environment and culture of care; and resources for maintaining dignity in care.

These themes are apparent in the work of the Department of Health in developing the 'Dignity in Care' campaign. A range of listening events with older people and their carers was held across the country which provided the basic evidence used to define the issues to be addressed in the 'Dignity in Care' campaign. In addition a Department of Health Survey obtained the views of professionals and members of the public online over a ten week period (from June to September 2006) regarding dignity in care (see also section 3.1.)

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[3]   Calnan M. Views on dignity in providing care for older people Nursing Times 2005 101

The Department of Health online study is criticised by academics ,who do not appear aware of the scope of the original listening events, in terms of sampling and lack of clarity in methodology, but is accepted as the 'official account' providing the background to policy. Ten key issues and two minor issues were identified:

1. Clarifying what dignity is – findings suggested that there is no clarity about what dignity is and what minimum standards should be. Responses suggested a range of meanings, for example, privacy, courteous treatment, having choices about care and consideration for cultural and religious needs.

2. Complaining about services – it was reported that 'the overwhelming majority of people who completed the survey' felt that It is difficult to make a complaint about services, that the complaints system is not adequate and needs to be more accessible, simpler, quicker to respond, more independent and more powerful.

3. Being treated as an individual – responses suggested that people were not listened to or treated as an individual and that they were being cared for as a group. Suggestions for good practice included: talking to people as individuals and not stereotyping them; encouraging independence and giving people time and choice.

4. Privacy in care – People reported not having enough privacy when receiving care. The environment is important here e.g. ensuring that curtains and private rooms are available and also protecting privacy of information.

5. Assistance in eating meals – It was reported that there is not enough assistance available or time allocated to service users to eat meals.

6. Access to lavatory/bathroom facilities – There is often insufficient access to lavatory/bathroom facilities with staff unavailable to help and alternatives, such as commodes, offered that people found embarrassing and undignified.

7. Being addressed by care staff appropriately – Responses emphasised the importance of using proper titles and not calling people 'love', 'dear', 'poppet' and so on.

8. Maintaining a respectable appearance – Lack of care, time and resources and laundry damage were said to contribute to people not appearing well-groomed.

9. Stimulation and a sense of purpose – it was felt that lack of stimulation can speed decline and make people feel isolated, therefore, having stimulating activities and a sense of purpose (when in a care home or at home alone) are important.

10. Advocacy services – People suggested that there are insufficient advocacy services for vulnerable adults and that these would support people in making complaints.

The two other issues were identified as "common issues" but as they received a smaller number of comments were labelled "minor issues". Academic reviewers suggest this is possibly the result of the use of a self-selecting sample and the on-line methodology and is an

inappropriate distinction given the potential of these issues to diminish dignity for service users. The two items were:

1. Language barriers between care staff and service users – Responses pointed to difficulties in communication and cultural differences in care.

2. Mixed-sex facilities – Being placed in mixed-sex facilities makes many people feel uncomfortable

This review suggests these detailed issues are too specific and limited to be useful in the development and assessment of dignity in care programmes and that a thematic approach would be more valuable where each area conceptual area can be assessed and the needs of the organisation defined. The following themes are proposed:

- Environment of care
- Staff attitudes and behaviour
- Culture of care
- Specific care activities

How might dignity be operationalised in the care of older people?

To operationalise dignity in everyday practice, it is suggested that nurses should focus on the four themes discussed above. What is also required is the exercise of practical wisdom on the part of policy makers, managers and practitioners.

There are still gaps in our understanding of dignity, for example, in relation to different perspectives of people in different cultural groups, but enough is known to focus on operationalising respect for dignity in nursing practice.

This will require resources for research, education and for action-oriented practice development activities that make a difference to the dignity of patients and staff. Although dignity has been identified as a complex phenomenon, promoting it in everyday practice is neither mysterious nor unachievable. Operationalising dignity requires Government investment and professional will to commend and reward dignity-promoting practice and to respond speedily and constructively to those practices and behaviours that diminish dignity

2.1.2 Dignity in older age: what do older people in the United Kingdom think? Gillian Woolhead, Michael Calnan, Paul Dieppe, Win Tadd. Age and Ageing 2004 33 No.2 P165-170

Relevance – This is a summary of the UK section of a major international project on European older peoples views on dignity in care. Aspects of this study are covered in a number of reports

and it has a central role in the development of broader thinking on dignity in care in health and social care

Overall Aims
To explore the concept of dignity from an older persons perspective

Methodology
15 focus groups and two individual interviews were conducted in 12 different settings, with a total of 72 participants. Participants were purposively sampled to ensure a mix of socio-economic status, ethnicity, gender, age (65+) and level of fitness. The method of constant comparison was used to analyse the data.

Key Findings
There was strong evidence to suggest that dignity was salient to the concerns of older people. Dignity was seen as a multi-faceted concept:

- Dignity of identity (self-respect/esteem, integrity, trust);
- Human rights (equality, choice);
- Autonomy (independence, control).

Examples of dignity being jeopardised rather than being enhanced were given. A loss of self-esteem arose from being patronised, excluded from decision-making, and being treated as an 'object'. Lack of integrity in society meant that there was an inability to trust others and an increased vulnerability. Equality was an important issue but many older people felt that government policies did not always support their rights.

This work identifies the different ways dignity is conceptualised by older people. The evidence showed that person centred care for older people should be specifically related to communication, privacy, personal identity and feelings of vulnerability. It provides evidence for policy makers and professionals to tailor policies and practices to the needs of the older person.

At a time when notions of choice, empowerment and consumerism are high on policy agendas the study concludes there is a clear room for considerable improvement in practice.

2.1.3 Dignity and Older people: The voice of professionals. Sergio Arino-Blasco, Win Tadd and Josep Antoni Boix-Ferrer. Quality in Ageing- Policy, Practice and research Vol6 Issue 1 June 2006

Relevance – This study provides a summary of the views of professionals on the issue of dignity and older people as part of a major study for the Dignity and Older Europeans Consortium

Overall Aims

The overall aim is to understand health and social care professionals' views of various aspects of dignity and older people and to aid policy development to enhance dignity in care.

Methodology

Between October 2002 and March 2003, 85 focus groups were held involving a total of 424 professionals in six European countries. Participants were purposely selected to represent different occupational groups, different levels of experience and seniority and the provision of care in different settings. Participants represented medical, nursing, managerial, paramedical and social work professions from a range of employment settings, including hospital, residential and community.

Key Findings

The following major themes were discussed:

- **Professionals' views of older people and working with older people** - the majority of professionals found their work with older people enjoyable and satisfying
- **Professionals' views of dignified care** – Care that promotes autonomy, independence, engenders respect, maintains individual identity, encourages involvement, adopts effective communication practices and is person-centred and holistic is likely to maintain the individual's dignity.
- **Professionals' views of undignified care** - Undignified care fostered invisibility, depersonalised or objectified the individual, was abusive and humiliating, narrowly focused and disempowering.
- **The system** - Participants were unanimous in their criticisms of the system, claiming that deficits affected their ability to provide dignified care. Prevailing ideologies of managerialism and an 'economic approach' meant that older people's care was not a priority. The delegation of care responsibilities to various agencies or to unsupported family members resulted in a lack of co-ordination and integrated care. Growing staff shortages and resource restrictions, all made the provision of dignified care difficult.
- **Guidance** – Most participants agreed that greater institutional guidance would have a positive effect
- **Education for dignity –** few participants had received any professional education about dignity. Training should be practically focused and the use of mentors would be valuable.

Dignity is widely identified as a core value impacting on the various dimensions of the human being and should be fundamental in developing appropriate professional attitudes in health and social care. Awareness and education on human dignity supported by policies and resources will result in a better care system for all of Europe's older people.

2.1.4 Dignity: The voice of older people. Tony Bayer, Win Tadd and Stephan Krajcik. Quality in Ageing- Policy, Practice and research Vol6 Issue 1 June 2006

Relevance - This study provides a summary of the views of older people on the issue of dignity as part of a major study for the Dignity and Older Europeans Consortium

Overall Aims
The aim of the study was to explore how older people view human dignity and how it was experienced in their lives.

Methodology
89 focus groups and 18 individual interviews were held between April and October 2002 and involved 391 older people in the 6 participating countries. Recruitment strategies were purposive and ensured a mix of participants from a range of educational, social and economic backgrounds. Males were under represented, despite most centres making considerable efforts to specifically involve more men.

Key Findings
Despite the wide range of backgrounds and situations of participants, there was substantial agreement about the meaning and experience of human dignity in their lives. Dignity was seen as a relevant and important concept which, if maintained, enhanced self-esteem, self-worth and well-being. In general, participants found it easier to identify situations when dignity was lacking than those when it was present.

Three overarching themes were identified:
- Respect and recognition (from others and for oneself),
- Participation and involvement – many participants felt excluded from various aspects of society and this impacted on their sense of dignity. Dignity was enhanced when their opinions were considered, they were involved in decision making and had opportunities to contribute to society.
- Dignity in care (together with the impact of dependency and loss of autonomy). Dignified treatment was especially important when someone was dying.

This study has developed a comprehensive account of the views on dignity and dignified care of older participants. In terms of correlation to the theoretical model of human dignity developed

during the project, of particular importance and relevance was the notion of **'dignity of personal identity',** not least because it is perhaps most vulnerable to the actions of others and many participants expressed the view that one way of demonstrating respect was to treat someone as though they were an individual, with a history, a unique identity and personal relationships.

Menschenwürde (expressed as the basic idea of **innate dignity of human beings**) was also important to many. It was from this that various human rights sprung, such as the right to life, to be treated equally and the right to have autonomy and choices respected. The '**dignity of moral stature'** was expressed in notions of appropriate behaviour and showing respect to others, while the 'dignity of merit' was expressed less frequently.

This study adds to the evidence that attention to dignity and providing dignified care has a positive effect on health and social outcomes, including the sense of well-being It suggests that for the dignity of older people to be enhanced, communication practices and issues of privacy, personal identity and feelings of vulnerability need to be addressed.

Education of all health and social professionals should pay attention to the meaning of dignity and to practices that enhance or detract from it. Policies and standards for enhancing older peoples' care and management need to go beyond the merely mechanistic and easily quantifiable to identify meaningful qualitative indicators of dignity in care.

2.1.5 UK Study of Abuse and Neglect of Older People: Prevalence Survey Report
Madeleine O'Keeffe, Amy Hills, Melanie Doyle, Claudine Mc Creadie, Shaun Scoles, Rebecca Constantine, Anthea Tinker, Jill Manthorpe, Simon Biggs, Bob Erens Prepared for Comic Relief and Department of Health June 2007

Relevance – This is part of a major study to identify the extent of abuse and neglect of older people and provides valuable background to the broader issue of policy making to enhance dignity in care in the complex area of dignified care for those living in their own homes.

Overall aims and methodology
This study forms part of a wider programme of research involving a literature review, focus groups with service-providers and stakeholders, a national survey of over 2000 older people and a feasibility study for researching elder mistreatment in care homes.

Key Findings
This study provides reliable estimates for the extent of abuse and neglect among older people living in their own homes in the UK. This is the first study of its kind in the UK and widens the evidence base for policy making.

The findings suggest that the problem of abuse and neglect of older people in the UK is comparable with that in other Western societies. The estimate of prevalence ranges from 2.6% to 4.0%, depending on whether neighbours and acquaintances are included. The problem of neglect was the predominant type of mistreatment

While the estimated prevalence of 2.6% may appear low, it translates into a significant number of older people who have experienced, or are continuing to experience, a problem, which may have serious effects on their health and well-being. Moreover, there are good reasons for thinking that the estimate is conservative and that some mistreated people, including some of those who are most vulnerable, will not have been included in the survey.

Prevalence of mistreatment increased with declining health status.

The study concludes that older people can be cast too much in a role of dependency and frailty and needing to be rescued. Better prevention with earlier intervention, more choice with a stronger voice, tackling inequalities and improving access to community services, more support for people with long-term needs would all be part of moving towards an abuse-free world. More work is needed to develop an evidence base for practice and service development to ensure that dignified care can be provided to older people living at home.

2.1.6 UK Study of Abuse and Neglect of Older People: Qualitative Findings
Alice Mowlam, Rosalind Tennant, Josie Dixon and Claudine McCreadie Prepared for Comic Relief and Department of Health August 2007
Relevance: This section summarises the qualitative stage follow up of the study outlined in the previous section and is valuable in indicating that suffering from neglect and abuse does not necessarily lead to a lack of autonomy.

Overall Aims
The key aims of the study are to assess:

- The impact of mistreatment on older people and, where relevant, their families?
- What forms of action older people take in response to the experience of mistreatment?
- How do older people negotiate taking action, what factors influence their choices and responses and what are the barriers to reporting mistreatment?
- What factors influence how older people experience and cope with mistreatment
- What coping strategies do those experiencing mistreatment employ?

Methodology
The study involved 36 follow-up interviews with older people who had responded to the survey and three interviews with older people accessed through specialist BME organisations. Twenty-

two of these involved incidents where the perpetrator was a family member, paid carer or close friend. The remaining cases involved neighbours, acquaintances and, exceptionally, strangers. Three interviews were also carried out with family members who had supported the older person.

Key Findings

Respondents reported a range of effects on their health, well-being and quality of life, reflecting views expressed in the focus groups. These included

- They had lost their self-confidence and were depressed or anxious
- They were nervous about leaving their house
- Their physical health had been affected

The research shows clearly that physical frailty or dependency does not, and must not, be equated with loss of autonomy or a lack of robust views about a situation and how to deal with it.

What clearly emerges from the interviews is that adversity does not mean collapse and capitulation. Although there were certainly a range of negative impacts and experiences, and some respondents found it less easy to cope, the resilience of other respondents was one of the most striking features to emerge from the data. This resilience could exist in the face of sometimes profound disabilities, serious health problems and adversity in personal relationships.

2.1.7 Care of the Elderly in the United Kingdom: Dignity under threat? A study of the experiences of older people in the United Kingdom Michael Calnan, David Badcott, and Gillian Woolhead International Journal of Health Services Vol. 36 No 2P355-375 2006
Relevance: This report is based on qualitative work and identifies a potential problem of a conflict between the culture of the health service and the aim of providing dignified care for all older people. This is an issue which the 'Dignity in Care campaign' aims to address. The study is valuable in addressing the needs of a range of older people with varying care needs.

Overall Aims

The aim of this study is to:
- Explore the meaning and experiences of dignity by eliciting beliefs and values from older people in general, not only from the frail and old-old or those who are housebound or in residential institutions
- Examine whether dignity is a salient issue, and how older people conceptualise dignity, whether these conceptions resonate with theoretical discourses,
- Examine in what contexts dignity is threatened and how older people manage these threats.

Methodology

Focus groups were chosen as the primary method of data collection. Participants were purposively selected according to predefined criteria to represent a mix of socioeconomic status, ethnicity, gender, age (young-old and old-old), level of fitness, and memberships of clubs and groups

Key Findings

Dignity and respect might be tied to basic rights and entitlements that are conferred on citizens in democratic societies and/or at the micro level through social interaction and mutual recognition, but if dignity and respect are fundamental and inherent in democratic society or daily life, it might be easier to identify contexts where they are threatened or challenged.

- Identity and citizenship are probably most threatened when individuals do not have the resources to protect their autonomy and resist dependency and exclusion
- The social position of older age may threaten dignity and respect by structuring or limiting the opportunities for participation and/or social recognition

Older people's discourse on dignity, mirrored "lay" concepts of health, in that it is multidimensional. The dimension that dominated the discourse was **dignity of identity** and how it was threatened, particularly when participants were required to use health and social care services. The informants emphasised both the need to maintain their self-esteem and self-respect and the need to be treated, particularly through interpersonal care, with "respect" and "recognition."

This concern with identity is reflected in the responses to the common practice of addressing older persons by their first name on early acquaintance (and without seeking permission). It also illustrated the stoical attitude of older, frail people, particularly in the face of increasing reliance on health and social care workers for their personal care, when they emphasised the need to be treated with respect - that is, in a polite and courteous manner.

The concern with privacy and keeping control (both physically and mentally) has implications not only for identity but also for autonomy, The concern about maintaining independence and not "being a burden" is prevalent in older people's discourse, irrespective of whether they are living in the community or in hospital or residential care.

There was also some evidence that dignity might best be served for the non-autonomous terminally ill by respecting advance directives and avoiding excessive prolongation of life.

The discourse on dignity was dominated by the dimensions of identity and autonomy, in addition a third element of dignity was identified: rights, and concerns about threats to controlling the right to live and die in the way they preferred. These views tended to be articulated by the young-old,

Some evidence of a moral discourse of exclusion and inclusion also emerged. Inclusion was related to proper conduct and deportment, and dignity and respect were conferred if people behaved appropriately. This was reflected in discourse about intergenerational tensions, the disrespectful attitudes of younger people, and the apparent mutual lack of respect of both groups toward each other.

In conclusion, the older people's discourses on dignity contained a number of different elements

- The dominant one was concern about the negative treatment and care of older people that posed threats to personal identity and autonomy.
- It has been suggested that the difference in the perspectives and realities of users and providers is so marked that it is unbridgeable. One of the keys to this problem may be time and the different time frames adopted by providers and users: the time-rich but undervalued older user as opposed to the busy time-scarce provider whose priority is to get through the tasks.
- This is compounded by the culture of the "new" health service, with initiatives to increase throughput and access and speed up the journey through care. This contrasts with the needs of older people. Without change, there is the danger that "institutional ageism" will persist in the health service.

2.1.8 Black and Minority Ethnic Elders' in the UK: Health and Social Care Research Findings – Minority Elderly Care – Policy Research Institute on Ageing and Ethnicity 2005

Relevance – This is a valuable and relatively substantial study including both users and providers of services for the minority elderly and covers a number of different communities with different needs. It indicates specific needs in terms of dignity in care for ethnic minorities, which could be addressed through the 'Dignity in Care campaign'.

Overall Aims
- To investigate the perspectives of minority ethnic elders on their needs and to establish criteria for levels of acceptability in services
- To assess the perceptions of mainstream health and social care providers concerning minority elders' needs

- To assess the services that such mainstream providers deliver and their assessments of minority organisations as providers of care
- To assess how ethnic minority organisations perceive the needs of minority elders, the services they deliver and how they assess mainstream providers.

Methodology

390 face-to-face interviews were conducted with BME elders from three different ethnic communities. 53% of the informants were South Asian, 23% Chinese/Vietnamese and 24% African-Caribbean. Interviews were conducted in the first language of the informant. The minimum age level for informants was set at 50 years.

101 health and social care workers were interviewed face to face using a structured questionnaire. Representatives from 50 organisations were interviewed

The interviews were undertaken in three locations in the UK: London, West Yorkshire and Scotland.

Key Findings
Black and minority ethnic elders
The findings reported below are limited to issues relating to dignity and respect:

Informants were asked about their service expectations and perceptions of health and social care services. There were differences by gender and ethnic group with regard to:

- Providing places for worship
- Providing professionals of the same gender
- Providing professionals of the same ethnic background
- Enabling clients to talk freely about religious needs with staff

The highest expectations related to being treated with respect; feeling safe and comfortable; having dignity respected and that professionals behave with integrity.

The highest gaps in service provision concerned: avoidance of waiting lists and delays; provision of information about existing services in elders' languages; having the necessary staff for good services for elders; ease of communication; information to be simple and understandable and information about rights to be given clearly

Many of the biggest gaps between expectations and perceptions had to do with information and communication, which clearly suggests that there is an information gap in service

provision. There are numerous things which can be done about this, for example: better use of the Internet as a patient source of information; hospital radio in minority languages; better liaison with BME voluntary organisations and use of social care institutions to provide information to users about other services and institutions.

Service providers

The highest expectations were that: clients' dignity should be respected; service providers should treat clients with respect; clients should be able to trust staff; and care staff should behave with integrity.

The lowest expectations were that: staff should be of the same ethnic background; of the same gender; services should be open at all times and organisations should provide places of worship.

The greatest gaps concerned: the possible use of alternative care methods; the provision of information in clients' own language; that staff should understand clients' cultural values; that care-providing organisations should have easy-to-follow procedures and processes.

Black and Minority Ethnic organisations

A wide range of organisations in terms of size and function were covered. More than half indicated the situation of their target groups was poor. These organisations had similar expectations in terms of services for older people as mainstream providers but were much less likely to believe these expectations were being met. They were overall far more critical of the level of service quality.

The widest gaps perceived between expectations and provision related to:

- Waiting lists and delays in providing services
- Alternative care methods should be accommodated within the existing care structure
- An interpreter should be available when minority clients are required to use care services
- Information about the clients' rights should be presented clearly
- The staff should have an understanding of the clients' cultural values when providing services

There is a thriving BME voluntary sector, which would like to expand its services to enhance those of mainstream providers. Both users and voluntary organisations saw bigger service quality gaps than the service providers and these perceptions need to be addressed.

2.2 Improving Dignity of Care in care homes

A limited number of studies have been carried out specifically related to the issue of dignity in care for older people in residential care homes. This possibly reflects a sector which is more disparate than the health service and where the majority of carers do not have strong bodies such as the Royal College of Nursing which has played a major role in understanding and advising on the practice of promoting dignity. Local activity summarised in section 4 however suggests clear attempts are being made locally to co-ordinate health and social care activity to enhance dignity in care.

2.2.1 A Phase II randomised controlled trial assessing the feasibility, acceptability and potential effectiveness of Dignity Therapy for older people in care homes: Study protocol Sue Hall, Harvey Chochinov, Richard Harding, Scott Murray, Alison Richardson, and Irene J Higginson BMC Geriatr. 2009; 9: 9 March 2009

Relevance The research addresses the issue of dignity in end of life care and the possible wider role of dignity therapy an approach developed for cancer patients. This article outlines the study protocol only.

Overall Aims

The aims of this study are to assess the feasibility, acceptability and potential effectiveness of Dignity Therapy to reduce psychological and spiritual distress in older people reaching the end of life in care homes,

Methodology

A randomised controlled open-label trial. Sixty-four residents of care homes for older people were randomly allocated to one of two groups: (i) Intervention (Dignity Therapy offered in addition to any standard care), and (ii) Control group (standard care). Recipients of the "generativity" documents were asked their views on taking part in the study and the therapy. Both quantitative and qualitative outcomes were assessed in face-to-face interviews at baseline and at approximately one and eight weeks after the intervention (equivalent in the control group). The primary outcome is residents' sense of dignity (potential effectiveness) assessed by the Patient Dignity Inventory.

Discussion

Dignity Therapy is brief, can be done at the bedside and could help both patients and their families. This detailed exploratory research aims to show if it is feasible to offer Dignity Therapy to residents of care homes, whether it is acceptable to them, their families and care home staff, if it is likely to be effective, and determine whether a Phase III RCT is desirable.

The approach was developed for cancer patients and may face practical problems amongst those with hearing impairments or minor cognitive impairments. It is hoped that if dignity therapy proves effective it will be a relatively low cost intervention which could be offered routinely in care homes.

2.2.2 Living and dying with dignity: a qualitative study of the views of older people in nursing homes Sue Hall, Susan Longhurst and Irene Higginson Age and Ageing 38 No 4 P411-416 May 2009

Relevance- This provides a follow up of the original feasibility study outlined above and is on a very small scale so needs to be treated with caution

Overall Aims
An empirically based model of dignity has been developed, which forms the basis of a brief psychotherapy to help promote dignity and reduce distress at the end of life.

The overall aim of the study is to explore the generalisability of the dignity model to older people in nursing homes.

Methodology
Qualitative interviews were used to explore views on maintaining dignity of 18 residents of nursing homes

Key Findings
The main categories of the dignity model were broadly supported: illness-related concerns, social aspects of the illness experience and dignity conserving repertoire. However, sub-themes relating to death were not supported and two new themes emerged. Some residents saw their symptoms and loss of function as due to old age rather than illness. Although residents did not appear to experience distress due to thoughts of impending death, they were distressed by the multiple losses they had experienced.

These findings add to our understanding of the concerns of older people in care homes on maintaining dignity and suggest that dignity therapy may bolster their sense of dignity.

2.3 Dignity in Care Policy guidance

This section covers specific guidance on the overall issue of dignity in care policy as provided by organisations including SCIE, Royal College of Nursing, and the Care Quality Commission and also covers briefly, related policy issues, such as progress on meeting the objectives set in the National Service Framework for Older People. This guidance has applications in terms of both national policies and in providing local guidance for the implementation of 'Dignity in Care campaigns' across health and social care.

2.3.1 SCIE Guide15 Dignity in Care – November 2006 (updated August 2007, February 2008 and March 2009)

Relevance – SCIE provides very valuable and extensive guidance on the policy background to the 'Dignity in Care campaign', summarises the range of research available relating to dignity in care overall and provides practice examples which can be used as part of local 'Dignity in Care campaigns'. This section summarises those findings relating to defining dignity and overall policy particularly relating to social care.

Summary of main points

SCIE has at the request of the Department of Health produced a guide for those working in the NHS and social care and for users.

Definition of Dignity:

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."

While 'dignity' may be difficult to define, what is clear is that people know when they have not been treated with dignity and respect. Helping to put that right is the purpose of this guide.

Overview of Policy relating to Dignity in Care

- The issue of dignity is a prominent feature in the new framework for health and social care services
- The Department of Health's Green Paper, 'Independence, well-being and choice' (2005) and subsequent White Paper, 'Our health, our care, our say' (2006), 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) has incorporated these into their new assessment framework, 'A new outcomes framework for performance assessment of adult social care' (2006).
- 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'
- 'Essence of Care: Patient-focused benchmarking for health care practitioners' (2003) offers a series of benchmarks for practice on privacy and dignity.

Factors that have been held responsible for the absence of dignity in the NHS and social care include:
- Bureaucracy,
- Staff shortages,
- Poor management
- Lack of leadership,
- Absence of appropriate training and induction
- Difficulties with recruitment and retention leading to overuse of temporary staff.

There are also wider societal issues, including ageism, other forms of discrimination and abuse. A great deal of work is needed to tackle negative attitudes towards older people, to bring about a culture change and to ensure that such attitudes have no place in the health and social care sectors.

The SCIE has also issued a practice guide 'Assessing older people with mental health needs'

2.3.2 Ten commandments for the future of ageing research in the UK: a vision for action Oscar H Franco, Thomas BL Kirkwood, Jonathan R Powell, Michael Catt, James Goodwin, Jose M Ordovas, and Frans van der Ouderaa BMC Geriatrics 2007 7: 10

Relevance – The workshop is valuable in highlighting the lack of a co-ordinated approach to ageing research and setting guidelines for action. This covers a broader spectrum of research than is relevant to the issue of dignity in care but is important in emphasising research to monitor policies to reduce ageism and encourage active ageing.

Summary of Key Findings

The House of Lords reported, ageing research in the UK is not adequately structured and a clear vision and plan are urgently required. With the aim of setting a common vision for action in ageing research in the UK, a 'Spark Workshop' was organised. International experts from different disciplines related to ageing research gathered to share their perspectives and to evaluate the present status of ageing research in the UK. A detailed assessment of potential improvements was conducted and the prospective secondary gains were considered, which were subsequently distilled into a list of 'ten commandments' listed below:

1. Ageing is a highly differentiated and malleable process. Therefore, the commitment must be to develop interventions that can affect the ageing process or the experience of ageing in order to extend healthy life expectancy, independence and well-being in old age.

2. Investments in ageing research should be significantly increased as they are likely to produce immense gains to both the economy and society, in particular to the quality of life, productivity and self-sufficiency of the rapidly growing older population group

3. Society must recognise that improving the quality of life (QOL), of older people, including the promotion of active ageing and the eradication of ageism, is one of the biggest challenges of the 21st century. This should translate into an integrated governmental policy for research on ageing as a key driver of QOL improvements.

4. Ageing research should reflect the complexity of the ageing process and integrate different dimensions of research into human healthy ageing, including the biological mechanisms and the socio-economic, cultural and psychological determinants of the ageing process

5. Healthy ageing research should concentrate on early, reversible stages of pathological conditions. As many lifestyle-related chronic diseases share common pathways of early disregulation (e.g. CVD, AD), the development of markers, diagnostic techniques and interventions that can be applied to prevent late stage disease is fundamental

6. Ageing research should build on and expand existing longitudinal cohorts. These are critical to understand longevity and must combine genetic, socio-demographic and environmental aspects. It is crucial that future efforts embrace the role of genetics in ageing research given the variability of responses of individuals to drugs, nutrients and lifestyles due to different polymorphisms

7. Ageing research should pursue 'best practice' early interventions by creating an evidence base for translation to society, by engaging directly with its end users and, in particular, by ensuring that older people are a key reference point.

8. Research to inform the development and uptake of information technology, assistive technology and inclusive design must be implemented in the construction and design of products, homes, urban environments, public buildings and transportation systems to eradicate potentially disabling environments to functionally-limited older populations

9. The void in clear leadership, funding and representation of ageing research in the UK must be addressed. In particular, additional resources must be allocated to under-funded areas of ageing research (e.g. healthy ageing) to complement existing commitments to research aimed towards end-point chronic disease

10. It is critical that an overall ageing research portfolio is managed as a single entity across the contributing disciplines, which individually and collectively enhance understanding about the determinants and interventions that affect active ageing.

2.3.3 Regulator pledges a louder voice for people who use health and social care services – Care Quality Commission 10th June 2009

Relevance – The report contributes to the overall dignity in care initiative in emphasising the need for people receiving care in hospital, in care homes and in their own homes to have a greater say in the way they are cared for and to involve local voluntary organisations in programmes. A number of these issues relating to care in hospital are also addressed in the Healthcare Commission Report September 2007 which is summarised in section 3.8.

Key summary points

The Regulator pledges a louder voice for people who use health and social care services Care home residents, hospital patients and people who receive care at home will have more say in improving the quality of care services than ever before, through Voices into Action, a charter for involving people in its work as the regulatory body for health and adult social care in England.

Dame Joan Bakewell, who was appointed the Voice of Older People by the Government last November,. said:

"It is an important principle that people who need to use health and social care services should be given the means to make their views known and to influence the way these vital services are delivered. This is particularly important for older people, and those who are disadvantaged for other reasons, who often go unheard in our society. That's why I'm giving my full support to Voices into Action."

The charter states that the Care Quality Commission will:

- Conduct regular studies to find out people's experiences of health and social care services
- Involve people who have experience of using services in its inspection work
- Set up special panels of people, such as one to represent the views of currently or recently detained mental health patients
- Consult widely on CQC policies and other topics, making a particular effort to reach people who are often missed out because of their disabilities or other circumstances
- Work with Local Involvement Networks (LINks) and seek ways of actively involving voluntary groups in the Commission's functions
- Develop ways of assessing how well service providers and commissioners are involving people

2.3.4 Care and support a community responsibility David Brindle. Joseph Rowntree Foundation November 2008

Relevance – Although this article is not directly concerned with dignity in care it provides guidelines for greater community involvement, which other commentators have suggested is vital for the development of the 'Dignity in Care campaign'. It also illustrates the greater difficulties of ensuring dignity in care outside a health service setting and to resolve any possible conflict between community involvement and personalisation of care.

Summary of Key Findings

It is imperative that care and support is reintegrated with, and owned by, the wider community.

Any new settlement on long-term care and support must address the apportionment of responsibility for its delivery as well as its funding. With the state's capacity limited and family input likely to decline, the wider community must expect to play a growing role. This offers an opportunity to end social care's marginalisation,

- Social care has become isolated from mainstream society and its recipients are cut off from their neighbourhoods and from each other.
- Care and support need to be reintegrated with, and owned by, the wider community, and the voice of service users must be amplified and heard.
- A comprehensive information and advice service provided by local authorities would help knit together a system that has become fissured and inequitable.
- Demographic and societal changes mean there will be a growing shortfall of family carers and an imperative to promote care and support from the community.
- The government espouses the principle of rights in return for responsibilities, and seeks to foster community empowerment, but is not clear enough about the implications for adult care and support.
- Difficult questions about family and community responsibilities are being ducked and the issues risk being overshadowed by a focus on personalisation of services.
- Initiatives to build social capital in communities and encourage volunteering can make an important contribution, but are unlikely to deliver large-scale solutions.
- Consideration needs to be given to a new form of social contract, making explicit the relative responsibilities of the state, family and community and offering incentives to deliver care and support.

2.4 Additional Reports relating to overall dignity in care policy

The reports below summarise the views of some relevant organisations concerned with the provision of overall dignity in care for older people and suggests possible developments in policy to facilitate progress, particularly in the need for an integrated approach to health and social care services.

2.4.1. Dignity in care- Malcolm Payne social care and palliative blog St Christophers Hospice

Relevance: Although this is a politically motivated blog it provides a useful summary of the policy stages, which led up to the Dignity in Care campaign and makes a number of helpful points for future development.

Key Policy Stages summary

- Green paper on 'Independence, Wellbeing and choice' Dept of Health 2005 – developed a vision of increasing independence of service users
- 'Our Health, Our Care, Our Say' – Department of Health 2006 – the consultation strongly supported the need for improvements in personal dignity in health and social care.
- Dignity in Care project 2006 – defined ten major and two minor issues about dignity (see section 2.1.1)
- SCIE key points from research and policy are as follows:
  - Being respected as an individual is very important to older people receiving health and social care services.
  - Older people want a workforce that is patient and takes the time to listen to individuals and does not rush care
  - Getting to know service users as individuals, people with a history, is key to providing person-centred care (Randers and Mattiasson, 2004[4], Jacelon, 2004[5],Owen, 2006[6],).
  - Staff respect for service users and their carers and relatives is enshrined in 'Standards for Better Health' this also encompasses respect for people's diversity
  - The [Essence of Care benchmarks for privacy and dignity](#) are based on the need for respect for the individual (DH, 2003). 'National minimum standards for domiciliary care' require that: 'The service should be managed and provided at all times in a way which meets the individual needs of the person receiving care, as specified in their care plan, and respects the rights, privacy and dignity of the individual (DH, 2003).
  - ' National minimum standards for care homes' states that: 'The principles on which the home's philosophy of care is based must be ones which ensure the residents are

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[4]   Randers *I* & Mattiasson *A -C.* (*2004*) Journal of Advanced Nursing45(1), 63–71

[5]   Jacelon C.S Managing personal integrity: the process of hospitalisation for elders Journal of Advanced Nursing 46 P549-57

[6]   *Owen*, T and NCHR&D Forum (*2006*) *My Home Life*: *Quality of life in care homes*. Help the Aged, London

treated with respect, that their dignity is preserved at all times, and that their right to privacy is always observed' (DH, 2003).

– The NHS core standards require that healthcare organisations have systems in place to ensure that 'staff treat patients, their relatives and carers with dignity and respect'

– The National Service Framework next steps aims to ensure that, within five years, all older people receiving care services will be treated with respect and dignity (DH, 2006[7]). The report acknowledges the need for wide-reaching culture change and zero tolerance of negative attitudes towards older people.

– Barriers to providing person-centred care have been identified as: increasing bureaucracy, tighter budgets and restrictive commissioning leading to limited time, poor and inconsistent management and a mixed picture on training (Innes et al., 2006[8]).

The blog is critical of the lack of detailed practical guidance within the SCIE work. This is less true of the RCN reports which list activities that might compromise dignity, people vulnerable to loss of dignity and how nurses protect dignity through privacy, good communication and the way in which they provide physical care. It appears that organisations such as the Royal College of Nursing may be best placed to provide detailed practical guidance tools to their members.

2.4.2 Written Evidence to the House of Commons Health committee by Help the Aged (DZ08) NHS Next Stage review July 2008

Relevance – This summary show key concerns with the direction of government policy and the lack of an integrated approach to the overall provision of dignity in care for older people across all services.

Key Evidence relating to dignity

The following evidence was given relating to getting the basics right and maintaining dignity:

- In 2007, the Annual Report on Healthcare Associated Infection showed one in five people reporting not receiving sufficient help to eat their meals and that 22% of people did not feel they were always treated with respect and dignity in hospital.

- The dignity is of a patient is fundamentally linked to overall quality of care received, from maintaining hygiene and nutrition standards, to communicating effectively with patients and ensuring privacy.

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[7]   Our health, Our Care, Our Say: A new direction for community services

[8]   Innes, A., Macpherson, S. & Mccabe, L. (2006) Promoting person-centred care at the front line, York, Joseph Rowntree Foundation/SCIE.

- In a fast-moving environment, some essential aspects of care can be forgotten. Often it is older people who bear the brunt of such lapses. The risk of malnutrition in hospital increases significantly with age.
- The review has drawn attention to the need to get the basics right with a focus on tackling healthcare associated infection. It also emphasises quality of care, compassion and dignity.
- These issues cannot be viewed as mutually exclusive and managed as isolated concerns. Staff need to understand that dignity is not a separate programme of work—a "nice to have" campaign—but is integral to the wider quality and patient safety agenda.

We cannot afford to let dignity become a throwaway term, used by everyone but understood by none. Help the Aged suggests nine care areas which contribute to maintaining dignity: eating and nutrition, privacy, communication, pain management, personal care, autonomy and choice, hygiene, social inclusion, end-of life care. Only if providers are held to account across all these domains as part of the commitment to monitor quality can we be sure that we are truly to make progress on ensuring overall dignity in care.

The overall conclusions are highly critical:
" The concept of integration both within health and between health and social care services is largely missing. Furthermore, the failure to offer clear guidance on expectations of PCTs beyond a set of high level principles risks at best a postcode lottery of service availability and at worst a large scale disregard for the needs of older people Overall, the hands-off approach adopted by the Government in carrying out this review and making recommendations raises some serious questions over how the next ten years will play out for the rising numbers of older people requiring health services. If older people continue to disproportionately bear the brunt of poorly planned and coordinated services it will be indication that Government is abdicating its responsibility to look out for the interests of all users"

3. **National studies relating to the 'Dignity in Care campaign'**

This section summarises a number of studies which either led up to the 'Dignity in Care campaign' or provide overall guidance on the development of dignity in health and social care and on approaches which might be used to evaluate progress in the future.

3.1 'Dignity in Care' Public Survey October 2006 Department of Health

Relevance This study followed up a wide range of listening events with older people and their carers across the country which were used to define the 'Dignity Challenge'. The objective of this study was to broaden consultation to members of the public and professionals in health and social care. The methodology however is subject to some criticism in terms of sampling and the findings in terms of issues are seen by some academic reviewers as too specific and detailed. This is however possibly based on a misconception of the role played by these findings in the campaign development and a failure to take into account the earlier consultations.

Overall Aims

To gain feedback from the public and professionals about their experiences of being treated with dignity in care and to provide guidance for the DH to work with stakeholders to improve standards.

Methodology

The survey was carried out online and 400 people – members of the public, professional health and social care staff took part over a 10 week period. Responses were evenly divided between professionals and members of the public the majority of whom were carers and were commenting on care a member of their family had received.

Key Findings

There are ten major and two minor issues raised. These have been summarised and criticisms of the methodology discussed in the literature review - '2.1.1 . Dignity in the care of older people – a review of the theoretical and empirical literature Ann Gallagher, Sarah Li, Paul Wainwright, Ian Rees Jones and Diana Lee BMC Nurs 2008 7 11'
The most common issues raised are:
- Make it easier to complain
- Improve the inspection and regulation of the service
- Raise awareness and understanding of dignity in care.
The DH intends to work with key stakeholder to address these concerns.

3.2 Defending Dignity- Challenges and Opportunities for Nursing Baillie, L., Gallagher A., and Wainwright P London Royal College of Nursing 2008

Relevance – The study provides valuable feedback on the views of the nursing profession but is based on an electronic questionnaire sent to all members with a relatively low response rate.

Overall Aims

The RCN Dignity survey is one of a range of initiatives that underpin the RCN Dignity campaign The survey was designed to gain the perspectives of nurses, health care assistants and nursing students regarding the maintenance and promotion of dignity in everyday practice

Methodology

The survey was designed, based on initial qualitative work, as an electronic survey sent out to all members. 2,047 questionnaires were completed. Respondents worked in a wide range of roles in diverse practices.

Key Findings

The survey found:

- A high level of awareness of dignity and sensitivity to dignity issues amongst staff
- A strong commitment to dignified care
- Three main factors maintained or diminished dignity – the physical environment and the culture of the organisation, the nature and conduct of activities and the attitudes and behaviour of staff
- Nurses expressed the belief that the culture of the organisation (management bureaucracy/ target driven managers) compounded the problems with the physical environment in terms of lack of material resources
- Government policies were identified as both supporting and undermining dignity in care. The creation of a performance driven culture has led to some benefits for some patients but has the potential to undermine dignity in care. The government has declared 'zero tolerance' of undignified care but continues to allow mixed sex accommodation and sets management targets that may be inherently undignifying.
- Nurses feel they have inadequate time and resources to deliver dignified care.

The study recommends:

- **The government** should consider the paradoxical nature of its policies, make renewed commitment to single sex wards, improve nurse/patient ratios, involve nurses and health care staff in the design of health care environments
- The role of **employing and educational institutions** should be to:
    - Invest in the physical environment
    - Make patient care central to the organisational culture

- Demonstrate respect for the dignity of staff in tangible ways
- Provide training programmes to promote dignity in care
- Develop policies and practice that supports dignity in care including development of an ethical climate, appropriate organisational values and systems for reporting and whistle-blowing

- **The role of individual responsibility** is to take advantage of opportunities to develop understanding of dignity in care, engage in critical self-scrutiny, encourage feedback from others and be aware of the opportunity to enhance dignity by role-modelling.

3. 3 Four years on: The impact of the National Service Framework for Older People on the experiences, expectations and views of older people. Jill Manthorpe, Roger Clough, Michelle Cornes, Les Bright, Jo Moriarty, Steve Iliffe and OPRSI (Older People Researching Social Issues) Age and Ageing 2007 36(5) 501-507

Relevance – This study is a valuable approach using a variety of methods to rate the extent of progress in improving care for older people. It shows after 4 years that there are still major problems particularly within social care, which is still seen as fragmented and impersonal. This provides a major challenge for the' Dignity in Care campaign' development.

Overall Aims

The study aims to evaluate the impact of the National Service Framework for Older People (NSFOP) on the experiences and expectations of older people, 4 years into its 10 year programme.

The NSFOP is a comprehensive strategy designed to promote fair, high quality, integrated health and social care services for older people in England. It emphasises:

- The need for services to support independence and promote health
- The need for specialisation of services for key conditions (stroke, falls and mental illness)
- Advocates a cultural change in services so that the older people and their carers are treated with respect, dignity and fairness. It has a 10-year timetable for implementation, starting in 2001.

Methodology

A mixed methods approach to evaluation was taken in ten purposively selected localities in England. A portfolio of methods (listening events, nominal groups and interviews) was used with older people and carers to focus on processes as well as on outcomes and to allow for the possibility of conflicting or differing judgements about service quality.

Key Findings

- The National Service Framework for Older People (NSFOP) gave new direction to older people's healthcare and local government services in England by setting out a series of

service targets and provided a continuing impetus for system review and change at local level.

- A multi-method study of older people's views and experiences revealed that most are not aware of this policy designed to improve the quality of health and social services that they receive, some 4 years after its implementation.
- The timeliness and efficiency of primary care and hospital services has improved, but accessibility to general practitioners has worsened, social care is often described as fragmented and impersonal, and hospitals are perceived by some as risky, uncaring and disorganised around discharge.
- Older people understand the identity of carer and the need to support carers but are less likely to see themselves as having rights to good quality care.

3.4 The Challenge of Dignity in Care- Upholding the rights of the individual. A report for Help the Aged by Ros Levenson 2007

Relevance – This report provides a valuable and thorough review of the framework for understanding dignity as a preparatory stage for a major study. The findings are reported in some detail as they are likely to provide valuable input into the planned study.

Overall Aims

This report sets out a multi-faceted meaning of dignity, encompassing not just those well-known rudimentary aspects of care, but also the dignity inherent in treating people as human beings, and enabling them to carry on living life to the full, especially in the context of people receiving care. This is seen as 'the true, rich nature of dignity.'

Help the Aged defines nine domains which serve as a framework for understanding dignity, Help the Aged is developing a method of measuring progress across each of the key aspects of dignity outlined below.

Methodology

The report provides a review of the history of the development of the concept of dignity in care, the key principles involved and approaches to measuring dignity.

Key Findings

The following principles are defined:

- Dignity in care is inseparable from the wider context of dignity as a whole
- Dignity is about treating people as individuals
- Dignity is not just about physical care
- Dignity thrives in the context of equal power relationships

- Dignity must be actively promoted
- Dignity is more than the sum of its parts

Communication: The key areas where change is needed are to:

- 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

Changing behaviour on this fundamental aspect of dignity will require further efforts to challenge and eliminate ageism, a level of investment in care that does not force staff to be hasty in their communication and involves better training

Privacy: 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. 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 threat to dignity and privacy.

Self determination and autonomy: There are multiple sources of evidence that older people do not feel in control of how their services are delivered.

As people grow older and become users of care services, they are often discouraged from making their own decisions about acceptable levels of risk. One study found that older people living in institutions perceived themselves to have greater autonomy in decision-making than

older people receiving domiciliary care. Risk-taking is a vital part of autonomy, and the right to take risks is closely bound up with dignity.

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 falls short of what would be required to maximise dignity in care.

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 and carers.

Food and Nutrition: The SCIE report 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 is the will to put this into practice.

Pain and Symptom Control: Essentially, a more proactive approach is needed to ensure that the dignity of older people is not threatened by unnecessary pain or discomfort.

Many older people are unwilling to complain and worry about being seen as a nuisance. Some avoidable pain and discomfort is likely to be untreated because of a 'What do you expect at your age?' attitude.

This attitude and the failure to provide readily available basic healthcare treatment to relieve pain is not only morally reprehensible, but also arguably breaches Article 14 of the Human Rights Convention

Personal 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.

'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.

Personal Care and Help at Home: 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

Death with Dignity: Basic policy and good practice are 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 2006) has two aims:

- 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.
- 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.

Social Inclusion: Social exclusion is related to widespread ageism in society and 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 behaviour.

Older people themselves are well placed to take a leading role in working for an end to ageism, discrimination and social exclusion. The low level of the Personal Expenses Allowance is a matter for politicians but for a modest cost, the threat to dignity posed by some older people having insufficient means for personal needs and for some social life, could and should be altered

In addition there are some areas that need attention if dignity in care is to be safeguarded:

- Respect and recognition for staff and others who care for older people
- A new approach to education for staff working with older people
- Making better use of complaints advocacy
- A new approach to involving older people

Measures of Dignity in Care

The Healthcare Commission 2006 had been working on a Better Metrics project to improve approaches to measuring the performance of health services. Some of these are relevant to the 'Dignity in Care campaign' but are unlikely to address the nuances that are important to older people. Work is being progressed by the University of Sheffield on 'Care profiles'.

Measures of dignity in care must be person centred and have to draw on qualitative sources of information. Help the Aged suggest the following guidelines:

- Metrics for dignity in care should be devised and regularly reviewed in partnership with older people and their organisations.
- Metrics for dignity in care should cover the whole spectrum of care, including care at home as well as the full range of health and social-care settings.
- Metrics for dignity in care should be rights based and should incorporate human rights protected under the Convention of Human Rights.
- Metrics for dignity in care should include wider measures of tackling ageism and age discrimination, and promoting active ageing or older people, in line with individual circumstances and preferences.
- Metrics for dignity in care should include outcomes as prominently as processes, and these outcomes should be the ones that matter most to older people.
- Metrics for dignity in care should make full use of qualitative measures as much as quantitative measures.
- Metrics for dignity in care should include a small number of indicators that can be taken as proxies for dignified care in practice. However, these should not be taken alone as a guarantee of dignity; they should be used alongside robust qualitative data about personal experiences of dignity in care.

3.5 Measuring Dignity in Care for older people: A research report for Help the Aged Helen Magee, Suzanne Parsons and Janet Askham Picker Institute Europe 2008
Relevance: This is a key study in helping to develop research methodology to evaluate overall progress in achieving dignity in care through involving older people in the design of key measures.

Overall Aims

This study was carried out to identify indicators of dignity in care for older people. The aim was to make recommendations on the best way to measure each of the Help the Aged domains of dignified care outlined above: personal hygiene; eating and nutrition; privacy; communication; pain; autonomy; personal care; end-of-life care and social inclusion

Methodology

The research project was designed to involve older people, cover a range of settings where older people receive care, obtain data by carrying out qualitative research and to use these data to suggest some realistic quantitative and qualitative indicators and measures of dignity in care. It also makes comparisons with existing quantitative measures to assess how well our indicators map against those that already exist.

As far as primary research is concerned this is a qualitative study, but it also uses further secondary analysis and a review of previous research to extend the data collected, evaluate existing measures and say something about the key areas for action.

Key Findings

- As a result of this research, a draft set of proposed indicators across nine domains has been developed. The Picker Institute recommends to Help the Aged that it should adopt these as an initial set of indicators that can inform the further development of its work on dignity in care.
- The Institute recommends that these indicators should be promoted to the Department of Health and to the Care Quality Commission, including to those officials responsible for the Dignity in Care campaign, and those who are working to develop the metrics by which the CQC will assess the performance of health and social care service providers.
- The authors note, however, that any such set of indicators will require continual review and development. This study has shown that the concept of dignified care is complex and subjective. The measurement of dignity in care needs to reflect these complexities if it is to be genuinely meaningful.
- Existing indicators and survey instruments have been developed initially for use in primary or secondary healthcare, or in care homes. There is a relative lack of research among homecare service users.
- End-of-life care is a particularly challenging domain to measure, but a number of toolkits and guidelines for healthcare professionals have been developed which provide a good basis for the development of dignity indicators.
- Research participants emphasised that it was important to measure not simply *what* is done but *how* it is done.

Four cross-cutting themes were identified within the indicators:

- Choice
  - Support to make choices
  - Personalisation and tailoring of care
- Control
  - Respect for individual lifestyle
  - Preferences and involvement in decision making
- Staff attitudes
  - Respectful attitude in relation to all aspects of care
  - Courtesy and sensitivity in all forms of communication
- Facilities
  - Availability of and access to appropriate facilities/equipment
  - Cleanliness of facilities

List of proposed Indicators of dignity in care: what should be measured to assess whether health and social care services support the dignity of older users?

Dignity Domains	Choice	Control	Staff Attitudes	Facilities
Autonomy	Information to support decision making Choice in daily routines Choice of how to arrange own room in care home	Respect for personal property Involvement in decision-making about care and treatment* Freedom to complain without fear of repercussions Responsibility for long-term medication if desired Control over own life		Availability of advocacy services Specialist equipment to maintain independence available if needed Safety in own home
Communication	Being listened to Openness and clarity Information provided with sensitivity		Courtesy of staff Forms of address agreed with service user	Access to interpretation and translation
Eating and Nutrition	Choice of what, when and where to eat Availability of additional snacks	Respect for religious and cultural beliefs	Appropriate and Sensitive assistance to eat available when required Presentation of food	
End of Life Care	Information/support to make decisions Opportunity to discuss personal wishes Relief of pain and discomfort Choice of where to die and who to be with Care of body following death	Respect for advance directives/'living wills' Sensitivity to cultural/spiritual needs	Support for bereaved families and friends	Timely verification and certification of death
Pain	Choice of types of pain relief Opportunity to reject pain relief medication	Responsibility for own pain relief if desired	Appropriate and timely relief of pain/discomfort* Avoidance of care practices that cause pain where possible e.g.hoists Staff ask about/ acknowledge pain	Availability of a range of treatments to manage pain

Personal Hygiene	Choice of type/level of assistance Choice of who provides assistance	Use of own toiletries etc	Appropriate, timely and sensitive assistance	Sufficient, clean and suitable washing/toilet facilities
Practical Assistance/ personal care	Assistance that reflects user's needs and wishes* Respect for personal preferences/lifestyle choices	Support to maintain personal standards Agreed timetable of visits from carer or relatives	Respect for personal possessions	
Privacy	Permission sought before students or others are present during treatment or examination	Precautions taken to protect personal information	Privacy when using the toilet/ bathroom, or being examined, treated for or discussing condition* Permission sought before physical contact Protection of modesty	Single-sex facilities Availability of private space Curtains, blinds, use of 'do not disturb' signs
Social Inclusion	Equality of treatment*	Religious and cultural needs satisfied* Consulted about service-planning Opportunities to discuss impact of living situation on health	Valued as a person	Contact maintained with friends, family Cultural, recreational and social needs satisfied

A more detailed description of these dimensions can be found in the full report - 'Measuring Dignity in care for Older People'

3.6 Assessing Dignity in Care Jill Manthorpe- An assessment of 'Measuring Dignity in Care for Older People' Helen Magee, Suzanne Parsons and Janet Askham Community Care Jan 2009
Relevance - A valuable assessment of the work of Help the Aged/ The Picker Institute in developing approaches to measuring overall dignity in care, which raises a number of useful practice implications.

Overall Aims
To review the value of the Help the Aged study programme - The value of this study is revealed by a perceptive remark from the authors: "It is easier to make pronouncements about dignity than to ensure that dignified care happens." This is particularly the case for anyone responsible for measuring or assessing dignity in care.

Methodology

The article reviews the five-month study which set out to identify a group of indicators that could measure the extent to which older people are treated with dignity and respect by health and social care professionals.

Key findings

The review highlights a number of significant findings from the studies as follows:

- Over-70s often gave more positive answers than younger older people when asked whether they were treated with respect and dignity.
- The study focussed on dignity in care in hospitals and care homes but had less about social care.
- The importance of terminology is highlighted - 'personal care' is confused with 'personal hygiene' researchers suggest using the term 'practical assistance' but this could lead to ignoring the psycho-social benefits of supporting people at home.

The authors conclude from their own and others' research that we should use a set of indicators to measure dignity that includes common "core" elements, relevant to any care setting, together with indicators specific to a particular setting. They recommend that indicators should be part of the early work of the new Care Quality Commission (CQC)

The authors recommend that, before creating further indicators with which to measure their performance, it might be worthwhile considering how to promote support for care workers to help them meet the needs of older people more effectively.

Practice implications

A number of practice implications are defined to aid those involved in social care:

For those supporting these groups of people

- How much are you and your members involved in 'Dignity in Care campaign' activities and what are the channels of communication with local dignity champions?
- What are your members' main concerns?

For social care practitioners

- What help is available to services users to draw attention to breaches of dignity?
- How well are these connected to adult safeguarding services?
- Is dignity considered in service delivery?

For service commissioners

- What use are you making of the considerable number of current studies that explore indicators of dignity?
- How do complaints influence agreements with providers?

3.7 SCIE Guide 15: Dignity in Care – Overview of selected research

Relevance- This overview provides an excellent summary of the evidence relating to the key themes arising from research and has been included in this review although some information has already been commented on in the report. This is also relevant as it is likely to be the key source used locally in the development of 'Dignity in Care campaigns'.

Overall Aims

The aim of the guide is not to provide a comprehensive review of all research studies but to highlight key issues and debates

Methodology

The review is organised in terms of themes, which are followed in the summary below.

Key Findings

Public Policy Background

- 'Modernising social services' (DH, 1998) sets the tone for social services by acknowledging the importance of dignity for all service users.
- The 'NHS Plan' followed in 2000 by including a chapter on 'Dignity, security and independence in old age', and many subsequent documents developed the theme.
- The National Service Framework (NSF) for Older People (DH, 2001), which established a 10-year service development programme, 'was triggered by concerns about widespread infringement of dignity and unfair discrimination in older people's access to care'.
- Opportunity Age (DWP, 2005), the government strategy for improving services for older and more vulnerable citizens, also highlights the need to continue the fight against ageism and age discrimination, and defines one of the principles of service provision in terms of older people's entitlement to dignity, respect, freedom from abuse and good quality care.

What dignity means

The 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."

Or as one service user put it: **'Being treated like I was somebody'** (PRIAE/Help the Aged, 2001).

Ideas of dignity in a wide range of studies are reviewed including 'Dignity and Older Europeans, Woolhead et al (2004)[9], Calnan (2005)[10] and suggest there are a number of consistent and overlapping themes as shown below:

The meanings of dignity

Research with older people, their carers and care workers has identified four overlapping ideas of dignity:

- **Respect**, shown to you as a human being and as an individual, by others, and demonstrated by courtesy, good communication and taking time.
- **Privacy**, in terms of personal space; modesty and privacy in personal care; and confidentiality of treatment and personal information.
- **Self-esteem, self-worth, identity and a sense of self**, promoted by all the elements of dignity, but also by 'all the little things' - a clean and respectable appearance, pleasant environments - and by choice, and being listened to.
- **Autonomy**, including freedom to act and freedom to decide, based on clear, comprehensive information and opportunities to participate.

What protects dignity

The review identifies three key factors involved in protecting dignity

- **Resilience** - Studies have found that the inner strength and resilience of many older people enables them to bear situations which others might find challenging or disabling. Resilience can be reinforced or undermined by the practice of health and social care workers; and that the existence of this quality in older patients should not be used as a reason for underestimating the very real threats to their self-esteem and well-being in some care settings.
- **Rights** - Older people receiving care at home, in hospital or care homes have a wide range of rights, and some analysts (Townsend, 2006[11]) see the enforcement of these rights, and increased insistence on them by service users, as the best way to overcome embedded systems and outdated attitudes. They include the following: The Human Rights Act 1998, Mental Health legislation, Care Standards Act 2000 and the Equality Act 2006
- **Person centred care** – the following factors and benchmarks were identified in Essence of Care (2003)

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[9]   Woolhead G. Calnan M., Dieppe P. Tadd W. Dignity in older age: what do older people in the United Kingdom think? Age and Ageing 2004 33 165-170

[10]   Calnan M Views on dignity in providing care for older people. Nursing Times 205 101 38-41

[11]   Townsend, P. (2006) Policies for the aged in the 21st century: more 'structured dependency' or the realisation of human rights? Ageing and Society, 26, 161–179.

Factor	Benchmark of best practice
Attitudes and behaviour	Patients feel that they matter all the time
Personal world and personal identity	Patients experience care in an environment that actively encompasses individual values, beliefs and personal relationships
Personal boundaries and space	Patients' personal space is actively promoted by all staff
Communicating with staff and patients	Communication between staff and patients takes place in a manner which respects their individuality
Privacy of patient - confidentiality of patient information	Patient information is shared to enable care, with their consent
Privacy, dignity and modesty	Patients' care actively promotes their privacy and dignity, and protects their modesty
Availability area for complete privacy	Patients and carers can access an area that safely provides privacy

Threats to dignity

Many threats to dignity take place at a small scale, practical level and remedies have been suggested such as improved training, quality of management, supervision etc. Recent research suggests the need for more fundamental change focussing on the nature of society and the factors which act as barriers to dignity in care.

Specific issues reviewed include:

- **Ageism** which was becoming a common feature of access to NHS treatment and social care in the 1990's. In the National Standards Framework (NSF) for Older People's (2001), the government announced its determination to 'root out age discrimination'. Formal barriers to NHS treatment based on age were removed; procedures followed by the National Institute for Health and Clinical Excellence (NICE) were amended to ensure that access to treatment should be based on individual need rather than age

  Despite marked changes for the better in relation to explicit age discrimination, the report (Commission for Healthcare Audit and Inspection) notes evidence of ageism among staff across all services. This ranges from patronising and thoughtless treatment from staff to the failure of some mainstream public services [reflecting a] deep-rooted cultural attitude to ageing, where older people are often presented as incapable and dependent

- **Inequality, disadvantage and discrimination** Older people, like all people, may encounter prejudice, discrimination and exclusion because of any of these factors. They may confront old age already suffering from disadvantages which threaten their sense of autonomy and self-esteem or they may simply encounter service providers who are unable to understand or fully meet their needs.

The inspection (Commission for Healthcare Audit and Inspection, 2006) also reported that more work is 'required to ensure that older people from black and minority ethnic groups receive services which are culturally sensitive and responsive to their needs' A study by PRIAE/ Help the Aged 2001 found black and minority ethnic people in hospital had different priorities in terms of maintaining dignity. They raised issues of food, communication, staff insensitivity and racism and bureaucracy and staff shortages.

Studies in general argue for the need for further work to identify dignity issues for different groups of the population in different settings.

- **Abuse** - Abuse is a violation of an individual's human or civil rights by any other person or persons. A consensus has emerged identifying the following main different forms of abuse ('No Secrets' Department of Health 2000):
    – physical abuse
    – sexual abuse
    – psychological abuse
    – financial or material abuse
    – neglect and acts of omission
    – discriminatory abuse

Many of the themes which emerged from the research and stimulated debate about abuse have already been mentioned as threats to dignity in care. The Commission for Healthcare Audit and Inspection, 2006, identified increased awareness among care staff of how and when abuse and neglect could occur as a critical area for further development.

Dignity in practice
The overview summarises research in different settings:

- **At home** - An extensive review of literature (Godfrey et al., 2000[12]) on the effectiveness and outcomes in home-care services found 'very little emphasis on the service-user and care-giver well-being'. There was evidence from a range of surveys which showed that the qualities most valued by older people in home-care services were reliability, continuity and the quality of the relationship with the care worker. Women especially valued housework: 'having a clean home was viewed as a key factor in maintaining their sense of dignity and self-respect'.
  A long-term study (Patmore, 2005[13]), designed to establish the kind of home care which would promote well-being and choice among older people found that the most common

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[12]   Godfrey M, Randall T, Long A, Rant M. (2000) *Review of effectiveness and outcomes: home care.* University of Exeter, Centre for Evidence-Based Social Services.
[13]   Patmore, C. & Mcnulty, A., (2005) Making home care for older people more flexible and person-centred: factors which promote this. York, University of York: Social Policy Research Unit

ungranted wish among older home-care customers was for help to get out of the house, to improve morale and mobility. The relationship between individual care worker and customer was very important, but the role of purchasers was critical. A focus on the needs and wishes of the individual depended on purchasers, providers and care staff all believing in 'caring for the whole person'.

- **Acute hospitals** - Mobility and other key aspects of independent living are known to suffer as result of stays in hospital and other institutions, which can be particularly difficult to reverse for older people Older patients interviewed in other studies resisted attacks on their autonomy and dignity in hospital by using resilience to manage their situation and maintain their self-esteem (Jacelon, 2003[14]). Studies found particularly acute problems among older patients in maintaining dignity in intensive care.

- **Care homes -** 'Because the long-term care setting is both a residence and a place in which health care is provided, issues of autonomy take on greater significance and complexity than in hospital settings.' The quality of life in care homes has recently been reviewed by a consortium of Help the Aged and the National Care Homes Research and Development Forum, in collaboration with older people and representatives of the care home sector. The main messages resulting from this review have been published in My Home Life: Quality of life in care homes (Owen, 2006). They include several messages which are particularly relevant to dignity in care.

  - Maintaining a sense of identity is key to retaining self-esteem and a good quality of life. Person-centred care will support it.
  - Residents often feel that they want to be useful, and should be encouraged to use the skills and experience that they bring to the home.
  - Decision-making should be shared; and assumptions should not be made about who can and cannot give their views.

- **Mental health care -** All aspects of dignity in care are relevant to older people with mental health problems, but there are additional risks and barriers facing them. In care homes, for example, food and nutrition are important issues, but for a person with dementia or depression who is not given appropriate help with eating and drinking, the problem becomes critical.

  There is now a commitment to introduce the principle of geriatric consent to enable staff working with people with dementia to take account of their individual views and

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[14]   *Jacelon, C.S..* (*2003*) The dignity of elders in an acute care hospital. Qualitative Health Research 13(4), pp. 543-556.

preferences 'Raising the standard' (Cobban, 2004[15]), an action research project which took place between 2000 and 2002, looked specifically at how person-centred care was working for people with dementia and their carers. They found an 'under-trained, under-managed and under-valued' workforce, ill-equipped to deal with the demands of an increasingly complex set of needs. Despite improvements to the home care available to people with dementia, resources were still not adequate to meet demand for this key service, nor to achieve a consistently high standard.

- **Dignity in death** - As more people live into old age, palliative and end of life care are increasingly important aspects of caring for older citizens. Restoring dignity to death has two related elements:
  - End of life nursing practice. This involves supporting contact with valued family and friends while offering privacy when appropriate; and helping to preserve 'a sense of self' by controlling distressing symptoms and maintaining a pleasant environment. The importance of this environment has recently been recognised in the government's investment of £50 million in refurbishing adult hospices
  - The need of older people to have their grief at the deaths of contemporaries and companions openly respected

The main conclusions that can be drawn from this selected overview of the literature are as follows

- Some themes occur consistently many of which coincide with the findings of the Department of Health's online survey of people's views and experiences of care (DH, 2006).
- Dignity itself has proved very difficult to define. Researchers have struggled to tackle what is in essence a philosophical idea, and to tie it down with observation, interview and analysis. Everywhere, the literature reflects tensions and questions of balance: between preserving privacy on the one hand, and avoiding silent isolation on the other; between acknowledging autonomy and resilience, while offering close support; between actual frailty and dependence, and the need for usefulness; between setting clear service targets, and leaving room for flexible, personal responses.
- 'Dignity in care' obviously has meaning for older care users: Recognising and respecting what it means in terms of autonomy, privacy, respect, identity and sense of worth, and designing practice to support it, contributes to older people's well-being and - ultimately - to what makes their lives worth living. Dignity is never simple, but always important.
- There are a number of gaps in the research:
  - Problems of inclusion of older people with cognitive impairment

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[15]   Raising the Standard - An Action-based Research and Training Project Noni Cobban, University of Stirling

- Under representation of men
- Limited studies of older users of social care
- Limited research on the meaning and effects of ageism
- Lack of research on marginalised groups e.g gay and lesbian older people and some ethnic minority groups

3.8 Caring for Dignity – A National Report on dignity in care for older people while in hospital. Healthcare Commission September 2007

Relevance- The study is a valuable review in indicating progress made by a number of acute trusts in improving overall dignity in care but there are still a number of issues of concern particularly in terms of staff involvement with patients at ward level. Much of the information is based on self reporting. The report does provide some evidence of the success of the 'Dignity in Care campaign' in acute trusts.

Overall Aims
Findings from the NHS Inpatient Survey indicate that a high proportion of older inpatients are being treated with dignity and respect while in hospital, and many NHS trusts have declared compliance with standards relating to dignity in the Healthcare Commission's annual health check.

The Healthcare Commission decided to focus on 'dignity' as a key theme in the annual health check for 2006/2007 and to undertake a targeted inspection programme to assess the extent to which NHS trusts are meeting the standards relating to dignity in care for hospital inpatients.

The aims of this work were to promote improvement in care – firstly through an in-depth look at those trusts that appeared to be performing less well, and secondly to identify and share examples of good practice.

Methodology
The Healthcare Commission aims to assess the performance of trusts based on the following standards relevant to assuring that patients are being treated with dignity and respect
- C13a Healthcare organisations have systems in place to ensure that staff treat patients, their relatives and carers with dignity and respect
- C15b Where food is provided, healthcare organisations have systems in place to ensure that patients' individual nutritional, personal and clinical dietary requirements are met, including any necessary help with feeding and access to food 24 hours a day
- C16 Healthcare organisations make information available to patients and the public on their services, provide patients with suitable and accessible information on the care and

treatment they receive and, where appropriate, inform patients on what to expect during treatment, care and after care

- C20b Healthcare services are provided in environments which promote effective care and optimise health outcomes by being supportive of patient privacy and confidentiality

The declarations of the trust were checked against information from representatives of patients and the community. 35 trusts were identified as at high risk of non-compliance and were inspected.

Key findings

The following overall findings are outlined below:

- The profile of dignity had been raised as a result of the 'Dignity in Care campaign'
- There is still need for action to ensure that dignity becomes an integral part of the care process across all clinical directorates.
- The issue of single sex accommodation is still an problem for a number of trusts
- Nutrition issues are improving with use of volunteers, 'red trays' schemes etc
- Although policies existed in practice, older people were not always involved in decisions on their care – particularly patients with dementia. There were also issues with end of life care.
- Staff did not always have adequate training or support particularly in dealing with patients with dementia.
- Strong leadership from Trust boards is not always present and 'Dignity Champions' can make a real difference.
- Privacy was a key need both in terms of private space and privacy when receiving treatment. Innovative practice tended to be on a ward level.

The following recommendations were made:

- Trusts at board level must show commitment through having a named lead for dignity, clear policies, clear practice guidelines, recognising and understanding the spiritual and cultural needs of the local population and improving the handling of complaints
- Staff at ward level should develop more meaningful involvement with patients, their carers and relatives; nutrition should be treated as an integral part of care. Staff need increased support in dealing with patients with dementia and with end of life care issues. Dignity champions need to be more visible and active at the ward level
- SHA's need to work with trusts to ensure that agreed action plans are implemented
- Voluntary and community organisations should be more involved in helping older people make informed decisions
- Government policy momentum should continue and continuing support should be given to dignity champions

4.   Local initiatives and evaluating the 'Dignity in Care campaign'

There are a limited number of local studies relating to the 'Dignity in Care campaign'.

'Being treated with respect and dignity' is included in a number of studies of Patient Satisfaction with the health care service and a number of very small scale local qualitative studies have been carried out to inform the development of the campaign locally, some of which are listed below. They are not seen as formal attempts to evaluate the success of the intervention but are part of the process of developing practice. SCIE Dignity in Care practice guidelines list a number of these type of local studies and examples are given below. There is also very limited evidence of studies to understand specific local cultural needs.

Progress is being made in delivering Dignity in Care through Local Area agreements. Regional dignity leads have been appointed to 9 regions and a number of SHA's have set up clear strategies for the development of Dignity in Care e.g. North East and North West but there do not appear to be any clear plans for formal research projects to evaluate the success of interventions in either a hospital or social care setting.

 It is also difficult to identify what work is being carried out jointly across health and social care. At local level this appears to be controlled by joint scrutiny committees, which may have different titles e.g. 'Looking after ourselves,' in different regions. The work of a limited number of these committees are summarised below.

The sections below summarise a selection of the approaches of:
- SHA's and PCT's in developing 'Dignity in Care campaigns' locally
- Acute hospitals approaches to promoting dignity in care
- Health and social care joint projects on dignity in care

The review is not comprehensive as it was not possible to monitor the web sites of all hospital trusts, PCT sites etc within the time frame. The suggestion that certain areas have progressed more rapidly, particularly in the North of England, has been followed and a number of valuable examples have been obtained from the North West. Some examples have also been included of trusts identified as potentially failing in compliance with guidelines and show the real efforts that have been made to improve performance. Different aspects of the work of the SHA's in developing dignity in care overall are covered to illustrate a variety of approaches within the overall aims.

4.1 Strategic Health Authorities and PCT plans

The examples given below are not comprehensive but are illustrative of the type of approach made to incorporating 'Dignity in Care campaigns' into local policy. All SHA's are committed to dignity in care overall but there appears to be considerable variation in their level of specific commitment to excellence. The North West, at least from published information, appears to be one of the most committed areas.

4.1.1 NHS North West – Developing a North West service experience strategy

The importance of a positive service experience as a core element of delivering world class NHS service continues to grow in order of priority both nationally and locally. The North West SHA would be the first SHA to commit to such a region wide programme and would be well placed to act as a national demonstrator site for the development of more systematic approaches to the very best service experience The very best service experience captures both physical (access, waiting), emotional (empathy, compassion) and service experience. Evidence suggests that service experience from the NHS user perspective is at best variable but often poor. Yet research also tells us that a good physical and emotional experience can aid health and well being and is a factor in patient recovery and compliance with treatment.

Currently the North West is leading the way in many service experience programmes these include:

- **Patient Opinion:** a social enterprise procured by the SHA to provide an independent web-based platform for patient feedback to trusts, commissioners and MPs. The initiative aims to drive quality improvements from patient's stories by aggregating individual opinions and ratings into patient generated on-line reputations at ward, site and specialty level. Patients can provide comments and tips for improvement on any hospital service through a web-site exchange.
- **Patient Reported Outcomes:** based on the EQ5D questionnaire as recommended in the operating framework 2007/08, are currently being tendered for as part of the Advancing Quality programme for hip and knee surgery. These physical outcomes will focus on patient quality life measures e.g. pain relief, mobility and lifestyle
- **Nursing Care Indicators:** pioneered initially by St Helen's and Knowsley NHS trust, 7 quality indicators are now being piloted with 5 trusts across the SHA and picked up nationally as examples of good practice by the Department of Health.
- **Patient satisfaction surveys** are readily used by trusts and general practices as an indicator of patient experience. Examples include Bedside Patient Satisfaction

Questionnaires; the GP Patient Survey and technology assisted data analysis tools such as e.g. Dr Foster Patient Experience Tracker (PET).

Dignity, respect and cleanliness are considered the 'Brilliant Basics' which every patient should expect as a right. The Trust plans to go beyond this – NW chief executives have been asked to develop local programmes and initiatives to achieve this.

A pilot study on the use of empathy indicators is being carried out to understand some of the critical service experience questions that are not currently being addressed in the NHS from a patient perspective:

- **Do I trust you?** – To personally take responsibility for the care you give
- **Do you care about me?** – To demonstrate how passionate you are about my health
- **Are you committed to me?** – To fully explore my care options

Examples of local initiatives in the North West PCT's are included in the following sections. The work in Oldham which is moving clearly in the proposed direction is not summarised here as it is covered in background documents provided by the Department of Health – 'The Dignity in Care Campaign. Above and beyond NI 128: delivering Dignity through local area agreements' – Ruth Passman Senior Health Policy Advisor, Department of Health (see sources)

4.1.2 NHS South East Coast ' Improving the patient experience'

"Our patients expect – and generally get – excellent clinical care. But they also expect to be treated with dignity and respect. They want to minimise the difficulty of having to discuss personal and sometimes embarrassing conditions with strangers and they want to be able to protect their privacy and maintain their modesty."

The section below summarises individual PCT plans in the area to achieve this.

PCT plans
Brighton & Hove PCT
The PCT has been working with local NHS Trusts to develop detailed action plans to address mixed-sex accommodation issues locally and has developed a strategic approach to improving privacy and dignity. Detailed action plans have been prepared and their implementation will be rigorously monitored through the year.
East Sussex PCT and Hastings & Rother PCT
The PCT has reviewed the current situation within their community hospitals and reports that they are able to segregate male and female patients in all their in-patient units. PCT staff are working hard to ensure that privacy and dignity is maintained for all patients and this is

supported by the recent Patient Environment Action Team audits and the specific privacy and dignity audits conducted by the modern matrons.

Eastern & Coastal Kent PCT

PCT ambitions for 2008/9 include: development of Dignity & Privacy quality indicators for inclusion in contracts with trusts and providers; development of robust performance management arrangements and the development of a programme of learning events to share learning and good practice.

Medway PCT

Medway NHS Foundation Trust was referenced as one of the trusts in the Chief Nursing Officer's report as needing to improve. The trust has completed the NHS Institute for Innovation & Improvement, Privacy & Dignity self assessment checklist and implemented its good practice guide.

Surrey PCT

Surrey & Sussex Healthcare NHS Trust was referenced as one of the trusts in the Chief Nursing Officer's, 2007 report as needing to improve. The trust has since reviewed the Privacy and Dignity Policy and implemented a number of improvements. These include the development of a policy to minimise ward moves, and where this is required to communicate effectively with patients. The trust has also appointed "Dignity Champions" to address any arising dignity issues. Regular audits (three times a year) have been established using the nursing quality audit tool

West Sussex PCT

The PCT has reviewed trust compliance with standards for privacy and dignity and have plans to monitor using the Essence of Care Environment benchmark tool and NHS Institute for Innovation & Improvement's privacy and dignity self assessment checklist.

4.1.3 NHS North East Equality, diversity and human rights Annual report 2009

This is a report about what the North East Strategic Health Authority has done in 2008 to make the NHS a better and fairer place for patients and staff. It is called an 'Equality, Diversity and Human Rights' report because it shows the work which has been done to:

- Help all people to receive high quality health care, and help all staff to provide high quality care – we call this equality
- Recognise and celebrate the fact that every person, whether a patient or a member of staff, is an individual - we call this diversity
- Make sure every person, both patients and staff, is treated with dignity and respect - we call this human rights

The North East SHA is taking a human rights perspective on 'Dignity in Care'. The North East has the highest quality of healthcare according to the Healthcare Commission

4.1.4 NHS Next Stage review Yorkshire and Humberside – Report of End of Life Clinical Pathway Group- May 2008

The SHA has identified a lack of consistency across the area in the quality of the end of life experience. There is a need for both cultural and service changes.

There is a prevailing "live for ever" mindset amongst society at large and amongst the majority of health and social care professionals, which works against the normality of death and dying, and therefore hinders advance planning for end of life and gets in the way of a good death in the place where patients would choose to die.

Significant work needs to be undertaken to challenge this through the use of social marketing techniques, public service broadcasting, education, and more visible dialogue and activity which breaks down taboos around death and dying, bearing in mind the cultural diversity that exists within our society.

Commissioners need to specify clearly what needs to be in place to deliver good quality end of life care to their populations. They need to ensure that there is sufficient spread of care services providers available to deliver this. This includes sufficient specialist Palliative care services, hospice beds, services in hospitals and the community, and access to 24/7 nursing and support care, pharmacy services and equipment. Patients and carers should also have access to bereavement services, spiritual care and information.

Research will be needed to assess the impact upon the quality of care of best practice.

PCTs should also develop a clear action plan to address the recommendations in this report which in the short term should:

- Deliver the use of Liverpool Care Pathway in all nursing and residential homes, and as a matter of course throughout all hospitals, and roll out the use of Preferred Priorities of Care (PPC) and Gold Standards Framework (GSF) to level 4 across primary care.
- Ensure there is a single point of contact for patients, carers and families to access help and support for end of life issues, and that every end of life patient has a Key Worker.
- Ensure Out of Hours services specifications address end of life requirements and roll out the comprehensive use of end of life registers.
- Ensure the introduction of mandatory training and education on end of life issues in to continuing professional development for all staff involved in delivering end of life care
- Address any gaps in 24/7 access to district nursing services

4.2 Acute hospitals

The section below covers a range of acute hospitals activities. Hospitals which were shown by the Healthcare Commission to be in danger of non compliance are included. A number of examples are also taken from the SCIE Practice examples. Acute hospital trusts in general appear to have been active in their attempts to improve privacy and dignity in care.

4.2.1 Facilitating dignified communication (Ashford and St Peter's NHS Trust)

Ashford & St Peter's trust was one of the trusts identified in the Chief Nursing Officer's in May 2007 report as needing to improve - an extensive amount of work has been undertaken by the trust which was recognised as best practice in the September 2007 Healthcare Commission report *Caring For Dignity*

The trust's Communication Group looks at how the communication needs of patients can be met. Clinical care indicators monitor the fundamentals of care and the patient communication interview, undertaken by the Patients' Panel, highlights any areas of concern or best practice in regard to patients' communication. The group has undertaken extensive work to address the communication needs of individuals, in particular those with communication difficulties, and is currently building up a supply of equipment within the trust to facilitate more effective and dignified communication. These include RNID crystal loop listeners, wipe-clean A4 boards and speech amplifiers.

For further information contact

Harriet Stephens, Lead Nurse, Practice Development. Tel 01784 884940. Email harriet.stephens@asph.nhs.uk

4.2.2 Five factors of privacy (Southampton University NHS Trust)

The trust's Essence of Care Group, which carried out an audit to uncover areas of dignity in care that needed further work, identified five factors of privacy and dignity (206kb PDF file). Guidance was provided for all wards on the 'five factors' and they also developed a charter for patients (23kb PDF file) informing them of the standard of care they should expect.

4.2.3 'If only the experience could be different' (Luton and Dunstable Hospital Head and Neck Cancer Services)

Luton and Dunstable has taken an innovative approach to the ongoing re-design of their service, which is putting patients and staff right at the centre of the process. A project sponsored and supported by the NHS Institute for Innovation and Improvement is co-produced with Thinkpublic (a service design consultancy), anthropological researchers from University College London and, importantly, patients and staff.

The objective was to improve the experience of visiting the clinic. A team comprising patients, carers, healthcare staff, researchers and improvement leaders identified parts of the clinic process that heightened anxiety rather than reduced it, or contributed to patients' sense of helplessness. With thought, some small things could make a huge difference to the patients - for example, moving weighing scales out of sight of the waiting room: staff hadn't noticed how embarrassing patients found it to be weighed in front of everyone. The layout of the waiting room left patients facing a wall full of official notices or looking directly at others, and the number of different professionals around could be bewildering, so they are now trialling a different approach: instead of the consultants having rooms that patients move in and out of, patients now have rooms and staff move to see them.

See NHS Institute for Innovation and Improvement site for further details.

4.2.4 Improving first impressions (Stockport NHS Foundation Trust)

In 2004, Stockport NHS Foundation Trust established an initiative to improve the dignity and respect towards its patients via a campaign, which centred on a patient's first impressions of the hospital. These were based on patient correspondence, staff attitudes and the environment.
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Patient correspondence

Letters are often the first point of contact for the patient with the trust and should provide information in a reassuring, timely and accurate manner.

The First Impressions work led to the development of a consistent approach to patient correspondence, implementing standards for letters which reinforced the trust's image as a professional and caring organisation and inspired patient confidence in the services provided. It led to further work in improving the general information sent out to patients prior to coming into hospital, and the same information in video format on Patientline.

Staff attitudes

Widespread focus groups with staff led to a list of seven behaviours which all staff would be expected to demonstrate. These are known in the trust as the Dignity and Respect standards and staff have received training in how to meet them and how to train colleagues. They are:

- A tidy and professional image
- Personal introductions
- Listening and informing
- Taking responsibility for patients and customers
- Valuing staff and being a role model
- Telephone standards
- Treating patients according to their needs and beliefs

Large posters depicting these standards are placed around the trust with a telephone number inviting the public to let us know how the trust is doing.

The environment

This work stream concentrated on the public areas of the hospital, improving the appearance of the corridors, public toilets, waiting areas, entrances and outside areas.

The trust has now built on this by using Patient Advice and Liaison Service volunteers to ask patients for their views on their experience of the hospital. The issues raised, together with key issues from complaints and the national patient satisfaction survey, form the basis of a ward indicator framework which allows the Board of Directors to keep updated and assured of quality on a regular basis. In this way we aim to develop 'Ward to Board' reporting.

For further information contact

Judith Morris, Deputy Director of Nursing, Stockport NHS Foundation Trust, Tel. 0161 419 4049.

4.2.5 Assessing standards: South West SHA's audit tool

The SHA has developed an audit tool in the Somerset and Dorset area which aims at achieving high standards of patient dignity and putting patient experience high on the agenda. The audit tool is a template covering five key themes:

- Patient environment
- Privacy, dignity and modesty
- Communication with patients
- Promoting individual needs
- Staff training.

It also contains a scorecard so progress can be monitored and lapses can be picked up quickly and acted upon, using an action plan template.

For further information contact:

Sharon Waight, NHS South West. Tel 01935 384111.

Email Sharon.waight@southwest.nhs.uk

4.2.6 Dignity and Respect Training Project (John Coupland Hospital, Lincolnshire Teaching Primary Care Trust)

The John Coupland Hospital Older People project team has developed a Dignity and Respect Link Trainers Project in order to establish good practice throughout the hospital. Designated trainers were identified from several departments, each of whom was given special training and materials. These trainers in turn ran sessions for staff within their own departments. All existing and new staff will participate in the training.

For further information contact:

Maria Storti, Interim Operational Lead Intermediate Care, Lincolnshire PCT.

Email maria.storti@lpct.nhs.uk

4.2.7 Aintree University Hospitals Foundation NHS Trust Dignity in Care Challenge

To promote the 'Dignity in Care Campaign', Dignity/Older Peoples Champions were identified for every ward and department; this supported the initiative recommended by the Department of Health which was to improve the care delivered primarily to older people, although the Trust approach has been to develop Champions to improve care for all patients.

The Essence of Care, Privacy & Dignity Benchmarking Group carried out a survey of users' views which provided base-line data to inform the group of the challenges ahead and indicate the areas or issues which required specific attention. The NSF Older Peoples Steering Group audited staff knowledge and skills in caring for older people and incorporated the findings into a training programme aimed at clinical and non clinical staff who have patient contact.

Membership of the Steering Group and Dignity/Older People's Champion Network, have included a Non-Executive Director, Governors, Medical, Nursing and Allied Health Professional staff. Project streams have subsequently been set up to look at different elements of the dignity agenda to focus on improving patients' services and patient care i.e. from patient hospital clothing, curtain closures, involving student's with the dignity challenges to the transport of patients from area to area.

Contact: Sally Ferguson Director of Nursing and Patient services

4.2.8 Walsall Hospitals NHS trust Getting Better for Patients: Dignity in Care update

The trust was identified as one of the highest at risk of non-compliance in the Healthcare Commissions report. The Trust has implemented a number of initiatives to improve and monitor privacy and dignity including:

- A Dignity Policy was ratified by the Trust and a steering group set up
- A multi cultural advisory team has been set up and Impact Champions identified for areas of diversity.
- A 'My hospital experience' form is available to patients to complete on discharge and is available in 13 languages
- Environmental improvements have been made e.g. dignity curtains, bedside information folders etc
- Champions for older people were identified and have been given training and resources
- A red tray system has been introduced

4.3 Health and Social Care Joint Projects

Studies reviewed in the initial section suggested in general that the problems of developing dignity in care overall and the 'Dignity in Care campaign' were potentially more serious and difficult to solve in the area of social care in residential and nursing homes and in care of the elderly who remained in their own homes.

4.3.1 It's good to talk (Community Network)

Some older people may be too frail to leave their home and a telephone conference call can be the only link to the outside world. The national charity Community Network aims to help organisations tackle social isolation through the provision of 'social telephony'. Local authorities and voluntary organisations have worked with Community Network to facilitate regular sessions linking up older people who are unable to get out and about as they wish due to their own frailty, mobility, location or transport issues. These Friendshiplink groups have provided a lifeline for a group of people who might otherwise be unable to have any other social interaction in the course of the week. This example of helping to overcome social exclusion comes from 'A sure start to later life' (SEU / ODPM, 2006)

4.3.2 Report of the Healthier Communities and Older people Scrutiny panel on the Dignity in Care select committee Feb 2009 North East Lincolnshire

The key objective of the Dignity in Care select committee was to ensure that people receiving care in their own home, care homes, day care facilities and hospitals are treated with dignity as per the 'National Dignity campaign'.

The recommendations and concerns expressed were as follows:

- Need to improve quality of the residential and nursing home care in the region. Care Trust Plus quality framework needed encouragement to hasten its delivery
- The authorities should reimburse private care providers with training costs
- All care homes should have the services of an activities co-ordinator
- Appropriately trained volunteers should visit care homes to promote social engagement
- Clearer explanations should be given to service users refused admission to their first choice of care home
- Rooms within care homes with no en-suite facilities should be reserved for single occupancy
- Need to improve planning of the location of new care homes built and consider the development of a retirement village
- The use of volunteers and family members to assist at meal times should be encouraged
- The use of mixed wards in hospitals should be avoided
- Those receiving intensive home care packages should have continuity of carers

- Employees in all residential and nursing homes, home care providers, employees of the acute trust and Care Trust Plus should be issued with a Dignity Challenge card as a reminder of the elements of the National Dignity Challenge. Care Trust Plus were concerned that without a wider framework of training the cards were of limited value.

4.3.3 Leeds 'Dignity in care campaign' – Leeds Council and NHS Leeds

In Leeds older people were consulted about what they wanted health and social care staff to know about respecting and maintaining their dignity.

The key findings were incorporated into a series of posters with contact numbers for concerns or complaints about services. These were displayed in libraries, community centres and hospitals. This was followed by a series of postcards featuring the ten national dignity standards, local radio advertisements and leaflets.

Leeds council and NHS Leeds have had a scrutiny board inquiry into dignity across health and social services and have conducted dignity audits in acute care facilities. Dignity standards have been incorporated into commissioning contracts with providers.

4.3.4 Social care and health overview and scrutiny committee – 'Looking after Ourselves' April 2009 Wakefield city council

The committee launched an inquiry into dignity in care in October 2008 establishing a working group. Information was collected across the region and site visits made. The following recommendations resulted:
- Commitment to make training mandatory and based around the dignity challenge.
- Better liaison between care homes and hospital.
- More awareness training for doctors on A&E regarding difference between residential and nursing care.
- Commissioning to ensure dignity built into contracts.
- Personalised services – set of core values – dignity being one.
- Risk around self directed care – how should it be managed/monitored?
- Protected meal times to become a priority in hospital settings – board level commitment required.
- Monitoring of care plans should be routine practice in all care settings.
- Robust mechanisms must be put in place at all levels to monitor whether policies and practices are working and making a difference.
- Clear policies are required relating to dignity (including nutrition and privacy).
- The Acute trust to develop more meaningful involvement with older people and their families by making processes transparent, informative and responsive.

- Nutrition should be treated as an integral part of care. Assistance with food and drink should be provided in a manner that is dignified and centred on the individual.
- Appoint a dignity 'champion' from within the Overview and Scrutiny Committee.

4.3.5 Lancashire Dignity in Care charter- 2008

The charter is a joint initiative between Lancashire County Council and Lancashire social care partnership. This underlines the care a person should expect when they use care and support services in Lancashire

4.3.6 Manchester City Council Health and Wellbeing Overview and Scrutiny committee- July 2008

Manchester launched its own 'Dignity in Care campaign' at the 4th Manchester Social Care conference at the City of Manchester Stadium on October 24th 2007. Manchester has adopted the 'Dignity Daisy Standard' as its campaign emblem. The daisy symbol was inspired by excerpts from the poem 'If I Had My Life Over - I'd Pick More Daisies' by Don Herold.

The campaign is coordinated and managed by a steering group that includes representatives from all health and social care providers in the Manchester area. The Executive Member for Adult Social Care chairs the steering group and the Chair of the Health and Well-being Overview and Scrutiny Committee is one of its members. The 'Dignity in Care campaign' is linked to the:

- City Council intergenerational strategy
- Multi agency safeguarding strategy
- City Council Valuing Older People strategy

The steering group has developed an outcomes focused action plan promoting the principles through training, service delivery and the inspection, designed to ensure that all managers providing social care services have dignity champions
.
A Dignity in Care Award has been developed by the Dignity in Care steering group. The award recognises how service providers have integrated the Dignity in Care standards into day-to-day service delivery. A toolkit has been developed to help providers of care achieve 'Dignity in Care Status'. Park View Rest Home piloted the toolkit and was the first to achieve the award in February 2008, with residents and families being involved throughout the process, providing useful feedback and ideas.

Nine homes are currently using the toolkit to work towards the standard. Working groups are looking at extending the award scheme beyond Residential Care Homes to the next stage of homecare and learning disabilities. Safeguarding Adults is one of the linked groups

4.3.7 Activity in other North West areas

Reports are available for 'Dignity in Care schemes' in a wide range of areas of the North West including Oldham, Bolton, Wirral, Warrington, St Helens, Sefton and Blackpool. This region appears to have the greatest commitment to Dignity in Care working across acute hospitals and residential social care and in a number of areas is developing approaches which go well beyond the practical issues of privacy and mealtimes.

5. Summary and Conclusions

The literature review has covered both the overall identification of the issue of the need for improvements in dignity in care particularly for older people and the development of the 'Dignity in Care campaign' to move forward in meeting these needs in both health and social care. The results show general support from professionals and the public for both the concept of dignity in care and the campaign. The campaign is seen to have made progress in raising awareness and stimulating debate although there are a number of reservations expressed by a variety of organisations on approaches to defining issues and to methods of evaluation. Local priorities and approaches to dignity in care can be seen to be very varied.

Definitions of Dignity

Dignity is fundamentally concerned with claims of worth or value, with behaviour that justifies such claims and with treatment by others that shows appropriate respect - dignity is thus not reducible merely to autonomy or to respect. The Department of Health set out the vision for what dignified care looks like in terms of the ten point Dignity Challenge as shown below:

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.

In addition an online consultation with the public and professional staff raised ten major and two minor issues in defining and clarifying what dignity is:
- Complaining about services,
- Being treated as an individual,
- Privacy in care,
- Assistance in eating meals,
- Access to lavatory and bathroom facilities,
- Being addressed appropriately by staff,
- Maintaining a respectable appearance,

- Stimulation and sense of purpose,
- Advocacy services.

The minor issues are language barriers and mixed sex facilities.

Academic sources suggest a more a thematic approach would be more helpful in developing an integrated dignity programme across health and social care, which would allow for the definition of specific local needs but would provide a consistent overall framework for measurement.

- Environment of care,
- Staff attitudes and behaviour,
- Culture of care
- Specific care activities.

Practice guidelines could be given within each of these areas. This approach has been followed in the overview of SCIE(3.7) and Help the Aged/ Picker Institute studies(3.4 and 3.5)

What is clearly agreed by all sources is the central importance of dignity in care and the development of the campaign across the country is vital to achieving this objective. It is not a separate programme of work—a "nice to have" campaign—but is integral to the wider quality and patient safety agenda. Improvements in a number of practical aspects of dignity in care could be obtained with greater local commitment to put them into practice but the creation of dignity across all aspects of social care needs a more fundamental long term culture change.

Dignity within health care

There has been considerable progress through the 'Dignity in Care campaign' in Acute trusts in improving practice in terms of specific issues including improving privacy and dealing with nutrition issues. Ideologies of bureaucracy and managerialism and staff shortages work against the provision of dignity in health care for older people in the view of professionals. The long term issues relating to ageism, discrimination and abuse are still in the main to deal with.

A key element of dignity identified, which caused concern, was the right to die in the way you prefer and to avoid excessive prolongation of life. Progress has been made in this area through the campaign but there is concern that too many people die in hospital when this may not be their preference.

Studies indicate a number of issues in providing health care particularly in terms of communication and provision of information with dignity to members of ethnic minorities. They

also indicate the willingness of voluntary organisations to provide additional resources to the healthcare service to support the 'Dignity in Care campaign'.

Dignity within social care

The initial thinking around the campaign is thought to relate more specifically to care in hospital rather than to residential care or care in the community. The ideal situation is for an integrated approach across health and social care and there are a number of examples in areas such as Leeds and Manchester where the 'Dignity in Care campaign' has been developed successfully in this way.

Achieving dignity in social care is a complex task and factors that have been held responsible for the absence of dignity in social care include:

- Bureaucracy
- Staff shortages
- Poor management
- Lack of leadership
- Absence of appropriate training and induction
- Difficulties with recruitment and retention leading to overuse of temporary staff.

There are also wider societal issues, including ageism, other forms of discrimination and abuse.

Scrutiny committees do appear to be working successfully in a number of areas to co-ordinate 'Dignity in Care campaigns' across social care and health. This could be investigated further and would benefit from a systematic approach to evaluation. This appears currently to vary considerably by area.

Initial findings suggest that dignity therapy techniques developed for cancer patients may have a valuable role in care homes.

Dignity in care at home

This appears to be the least developed area in terms of the campaign. A different focus is required if promoting dignity for those living at home 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 need for stronger community based services which 'care for the whole person,' is identified across a range of studies The Care Quality Commission has emphasised the importance of providing a voice for older people cared for at home. Continuity of and the relationship with

carers is of particular importance in maintaining dignity of those cared for at home as is assistance in getting out of the house.

This needs to be an area for development of the dignity campaign and is likely to involve working in close co-operation with voluntary organisations, which from the limited research available, seem likely to welcome the opportunity.

Developments of metrics to measure dignity

The Department of Health set out ten issues in the 'Dignity Challenge' which could provide the basis for measuring progress in achieving dignity in care. Help the Aged have set up a major study by the Picker Institute to provide guidelines for measuring dignity in care. These are summarised in detail in sections 3.4 and 3.5. It is proposed that these could provide a basis for the development of an agreed approach to metrics for the evaluation of national and local studies.

Measures of dignity in care should be regularly reviewed with older people and their representative organisations.

Metrics ideally should be rights based and include measures of tackling ageism. They should include measures of outcomes as well as processes and make use of both qualitative and quantified measures. Quantified measures should be used alongside robust qualitative data relating to personal experiences.

National studies of dignity

Studies show improvements in dignity in care within hospitals but more limited progress within social care. There is a major need to involve residents in care homes in decision making, allow them to make use of their skills and provide person centred care to maintain a sense of identity. This is a difficult task due to the varied nature of the care facilities and a frequent dependence on temporary staff.

National studies show a real commitment to the 'Dignity in Care campaign' amongst nurses but they have concerns that government policy, staff shortages and the culture of the organisation may militate against them providing improved dignity in care.

The key threats to dignity identified are ageism, inequality, disadvantage, discrimination and abuse. There is a clear need for some attitude change in health and social care. There is limited evidence of trusts meeting the Healthcare Commissions requirement that they should exhibit a good understanding of the cultural and spiritual needs of their area.

Local studies of dignity

Some of the SHA areas particularly the North West show a real commitment to improving dignity in care within the health service and are working with social care to broaden the campaign to include all older people. A limited number of research projects have been carried out and most are small scale local projects. It would be valuable to attempt to evaluate the campaign over a region developing a research approach broadly based on Help the Aged proposals, to evaluate progress on practical issues and gain guidelines on aspects of the campaign which have worked in attempting to change attitudes.

The Way forward – developing approaches to evaluate the impact of the campaign nationally and locally

The 'Dignity in Care campaign' has potential to develop beyond the practical issues, which are being tackled in health care, to make a real contribution to the fundamental social problems of ageism, discrimination and abuse. In some areas it is inspiring people to take action locally and rewarding those who make a difference.

Key overall concerns

There is general agreement amongst staff, carers and older people that dignity in care is an important issue but there is some concern that this is a 'nice to have' campaign and needs development to deal with the underlying cultural issues in society that relate to ageism.

- The key issue raised is the need to use the campaign to improve levels of dignity in care for all older people. This involves a major cultural change to deal with the issue of ageism and not just the solution of practical, environmental issues.

- The need for integrated health and social care is highlighted – dignity in care must include care in hospitals, residential homes and in your own home for all older people and for those with complex mental health issues.

- Progress is being made on issues such as the need for dignity in death. It is important to ensure that some of the standards being introduced in hospitals are also met for those dying at home and that the choice of where to die is available to all.

Research development

Considerable work has been carried out by academic sources and in major studies, such as those for the 'Dignity and Older Europeans consortium', which has helped to create a good understanding of the meaning of dignity and is moving towards developing improved

approaches to measuring the effectiveness of the 'Dignity in Care programme' and of specific local developments of the campaign.

There are some criticisms by academics of aspects of the initial research involved in planning the campaign and in the lack of a co-ordinated approach to ageing research overall.

The work of SCIE is now attempting to integrate the work done across a range of governmental and non governmental organisations to understand how to evaluate the 'Dignity in Care campaign' across health and social care.

Studies on dignity in care at a local level are mainly limited to internal audits and overall patient satisfaction surveys. Some examples of qualitative studies and consultations are available which have been used in developing the 'Dignity in Care campaign' tailored to specific local needs. Research in this area is always likely to be complex as it involves consultation with those who may find it hard to express their views and needs a combination of qualitative and quantified approaches.

It would be of value to investigate how far those responsible for local health and social care provision are aware of the metrics developed by Help the Aged which academics view as a valuable basis for further development and of issues limiting research programme development locally.

Specific research issues which need to be recognised include:

- Problems of inclusion of older people with cognitive impairment
- Under representation of men in many studies
- Limited studies of older users of social care
- Limited research on the meaning and effects of ageism
- Lack of research on marginalised groups e.g. gay and lesbian older people and some ethnic minority groups
- Conceptual issues – it is easier for respondents to discuss dignity in its absence.

6.   Appendix

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John Coupland Hospital, Lincolnshire Teaching Primary Care Trust - Dignity and Respect Training Project

Aintree University Hospitals Foundation NHS Trust Dignity in Care Challenge

Walsall Hospitals NHS trust Getting Better for Patients: Dignity in Care update

Community Network - It's good to talk

North East Lincolnshire - Report of the Healthier Communities and Older people Scrutiny panel on the Dignity in Care select committee Feb 2009

Leeds Dignity in care campaign – Leeds Council and NHS Leeds

Wakefield city council Social care and health overview and scrutiny committee – Looking after Ourselves April 2009

Lancashire Dignity in Care charter- 2008

Manchester City Council Health and Wellbeing Overview and Scrutiny committee- July 2008