



Elder Abuse and the Dignity in Care Campaign

www.dignityincare.org.uk

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Elder Abuse

'A single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person'

Action on Elder Abuse 2009

'Abuse is a violation of an individual's human and civil rights by any other person or persons'

No Secrets guidance 2010



Elder Abuse

- Physical abuse
- Sexual abuse
- Psychological abuse
- Financial or material abuse
- Neglect and acts of omission
- Discriminatory abuse



Elder Abuse in the UK: Perpetrators

- Perpetrators of abuse are most often partners, spouses or other family members
- The most common type of mistreatment is neglect followed by financial abuse
- Perpetrators of interpersonal abuse are more likely to be male however males and females are equally likely to commit financial abuse
- Factors associated with perpetration include mental health problems, personality disorders, the quality of the carer/ person relationship prior to being cared for with better quality past relationships (eg more communal in nature) associated with more rewarding carer/ cared for relationships , less carer depression and potentially harmful behaviours
- Financial and housing dependency on the cared for individual have been associated with perpetration



Elder Abuse in the UK: Victims

- Much elder abuse remains hidden
- Elderly women are more likely to be victims of abuse than elderly men
- Reports of maltreatment are greater among those in the oldest age categories (85 and over) compared to younger age groups (65 to 85)
- The prevalence of maltreatment increases with declining health and impairment and is higher amongst those in receipt of care
- Factors associated with vulnerability to abuse include mental disorders, cognitive and physical impairment and social isolation

Institutional Neglect and Abuse

- The power of individual stories
- *•In the next room you could hear the buzzers sounding. After about 20 minutes you could hear the men shouting for the nurse, "Nurse, nurse", and it just went on and on. And then very often it would be two people calling at the same time and then you would hear them crying, like shouting "Nurse" louder, and then you would hear them just crying, just sobbing, they would just sob and you just presumed that they had had to wet the bed. And then after they would sob, they seemed to then shout again for the nurse and then it would go quiet"*

Independent Inquiry into care provided by Mid Staffordshire NHS Foundation Trust

Institutional Neglect and Abuse

- *"The nurses there weren't unkind to him, but they were overworked. We often felt that if we asked them if they would clean him up,... it would be hours before they came back to clean him up, and in that time he was just lying in a dirty bed with dirty nightwear on, and he didn't want me to go in the room, even. He would say: don't come near me, don't come near me, I smell; and he was a very fastidious man and he really was left lying in his own excrement."*
- *Independent Inquiry into care provided by Mid Staffordshire NHS Foundation Trust*

Mid Staffordshire Independent Inquiry

- Independent Inquiry into care provided by Mid Staffordshire NHS Foundation Trust
- •“While I have given some specific examples of poor standards giving rise to dignity issues, almost every case I quote of complaints about basic care is one in which the dignity of the patient has been compromised.
- •***It is difficult to imagine that in any such case those actually providing the care would have been content to be the recipient of such care themselves or to have seen a relative of their own treated in such a manner.***
- •However difficult the circumstances, there is really no excuse for hospital staff, at whatever level of seniority or skill, not respecting the dignity of patients”.
- Robert Francis QC



Elder Abuse: A Summary of Evidence for Prevention

Elder abuse- A preventable form of violence:

Promoting interventions to prevent elder abuse

Encouraging positive attitudes towards older people:

education programmes for health care workers and media campaigns

Providing support for caregivers: peer and professional support networks, respite care, psychological programmes to address and reduce caregiver burden and psychological distress

Increase identification and referral of those abused: use of screening tools and training for health and other professionals

Supporting those abused: through multi-agency work to ensure efficient management of elder abuse cases in the community



Elder Abuse: Legislative Protection

Offences against the Person Act, 1861

Public Interest and Disclosure Act, 1998

The Care Standards Act, 2000

Mental Capacity Act, 2005

The Domestic Violence, Crime and Victims Act, 2004

Safeguarding Vulnerable Groups, 2006

Human Rights Act and Human Rights in Healthcare framework
2008

Equality Delivery System-DH Consultations

Dignity Policy: Background

- Zero tolerance of neglect, abuse and indignity in care provision
- Building a Conceptual Framework for people's experiences of dignity in care. Research and literature review
- Measuring dignity and 'indignity' – One 'tool' with which to ascertain whether the dignity programme is delivering its aims.
- Dignity Framework: Contributions of organisational and individual knowledge and experience of dignity in care (e.g., CSCI, Help The Aged, BGS, GONW, Older Peoples Fora and Parliaments). Regional framework testing and baseline assessments
- Dignity is a key strategic objective of the Department of Health (DSO) and has been integral to the Local Government Performance Framework

Your Care, Your Dignity, Our Promise



Aims: Dignity Campaign

- **Raise awareness** of dignity in care
- **•Inspire** local people to take action in support of the campaign
- **•Share good practice** and give impetus to positive innovation
- **•Transform services** by supporting people and organisations in commissioning and providing dignified services
- **•Reward and recognise** those staff and teams that make a difference and go the 'extra mile'
- **Support the embedding of dignity in key processes**
e.g. Commissioning; workforce; quality; performance

The Dignity Challenge

The Dignity Challenge

High quality 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



The Dignity Framework

- The Dignity Map: Your Care, Your Dignity, Our Promise (YC,YD,OP) unites the elements of dignity into a single strategic structure.
- It aims to bring clarity to the concept and to display what high quality care for the elderly looks like (a similar structure to 'Every Child Matters').
- YC,YD,OP is a template that allows local care providers and care recipients to map out their Local Priority Indicators to reach the gold standard of ' people being treated with dignity and respect all of the time during care'.
 - NHS Constitution: Explicit recognition that a world class NHS must give a new priority to dignity and respect for patients

Mapping the aspirations of Government strategies

Putting People First

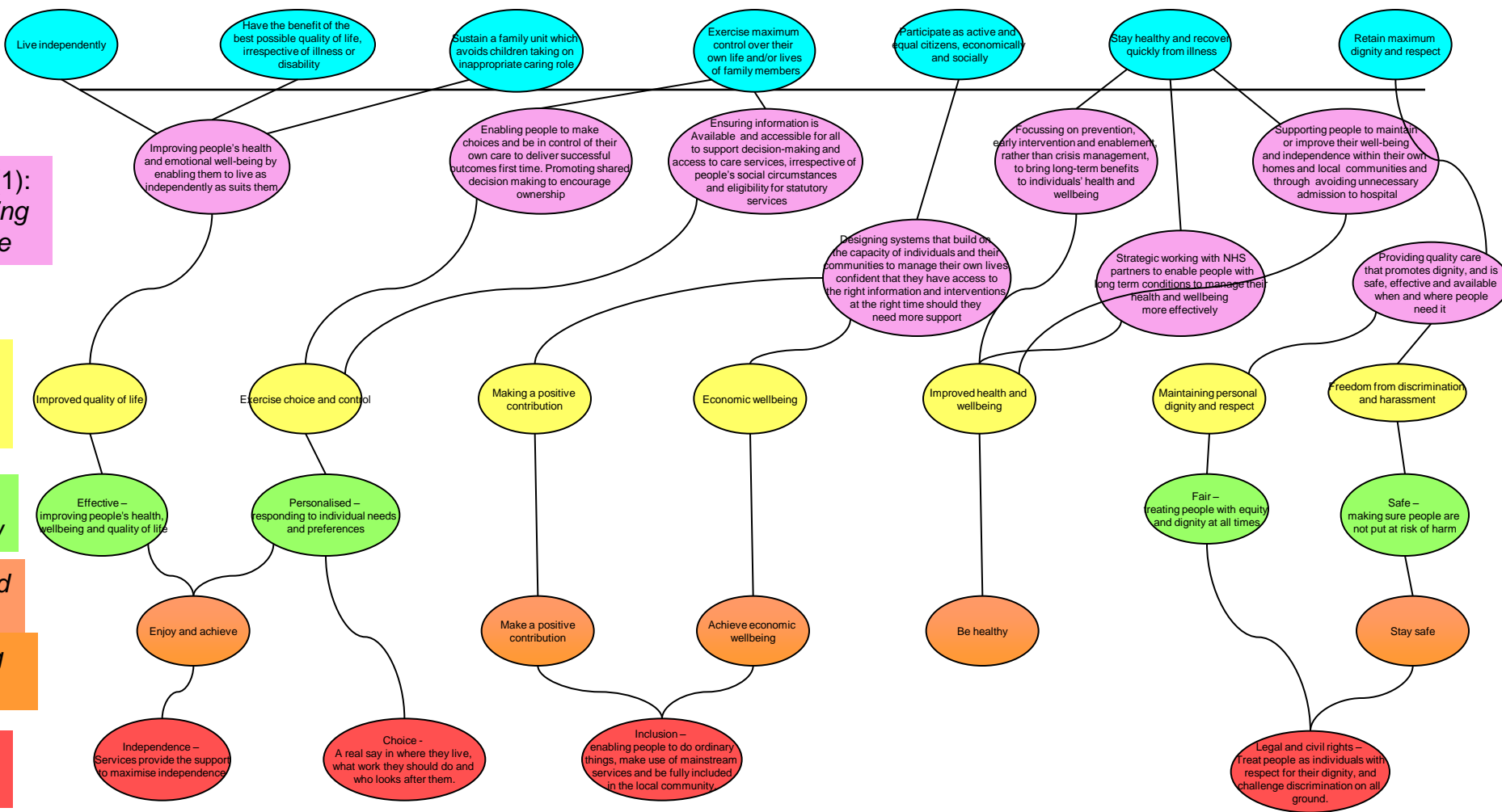
LAC 2008(1): Transforming Social Care

Our Health, Our Care, Our Say

NHS Next Stage Review

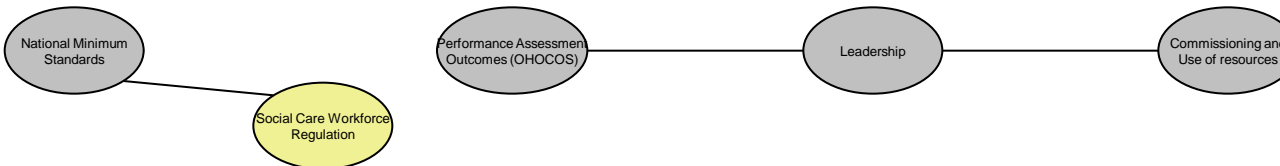
Every Child Matters Supporting People

Valuing People



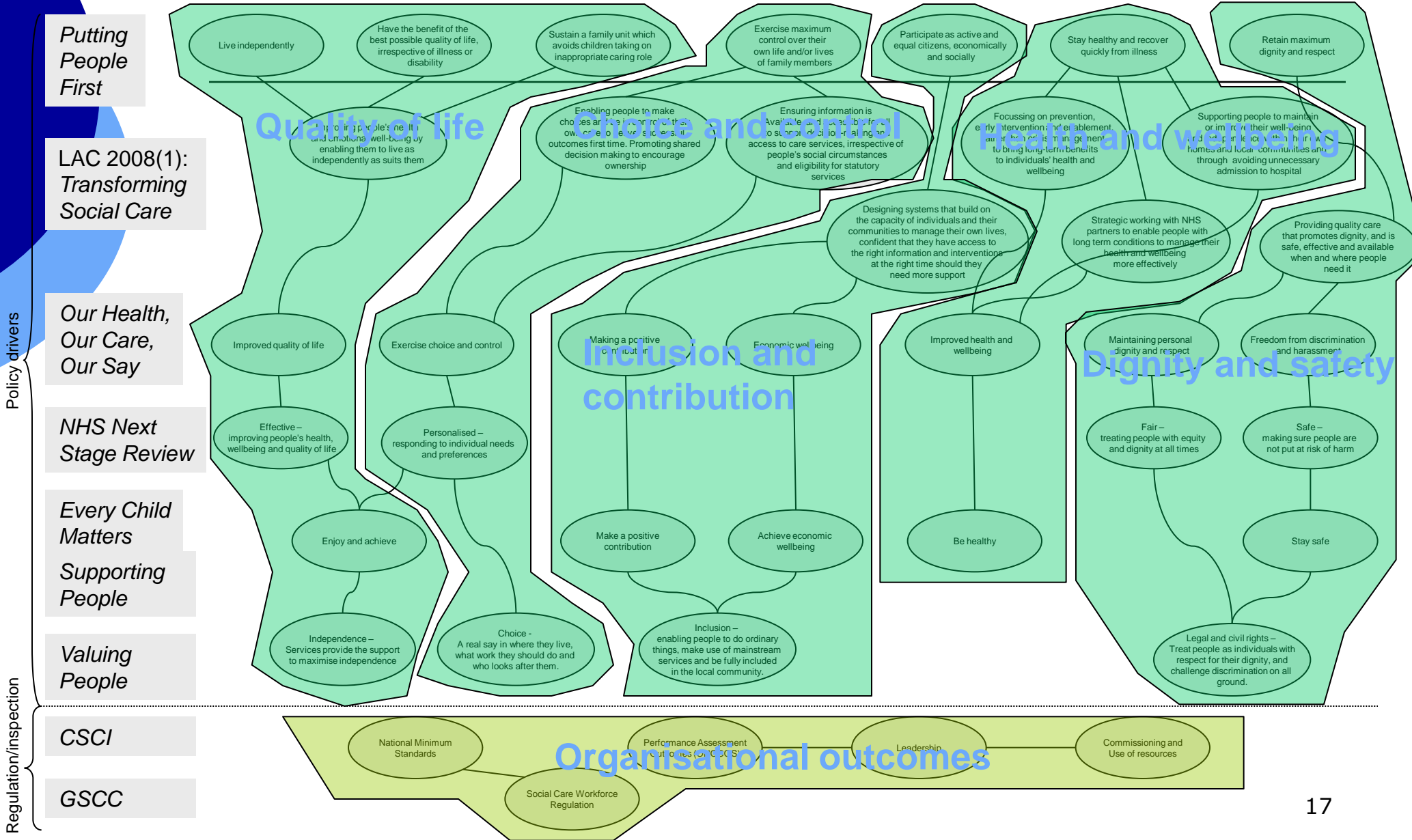
CSCI

GSCC



Quality / Dignity Spectrum

Grouping the aspirations into common themes



Dignity in all Care

- **Dignity in all Care** :Widening out the focus of the campaign. Dignity is elusive yet powerful
- **Dignity in Care Campaign Impact Assessment** in 2009 Evaluation of the Dignity in Care Campaign – strengthening and celebrating the role of Dignity Champions and frontline staff.
- **Dignity Framework to stimulate real change**
 - Open Source
 - User Generated Content
 - Co-Production
 - Collective Ownership
 - **What drives Dignity? – The conversation is more important than the answer**
 - Set Context – By raising profile of issue
 - Remove Barriers – By exploring concept
 - Provide Impetus – By encouraging innovation
- **Engagement, Involvement, Ownership**
 - Expressed through articulation of what success will look like to care recipients
 - Applicable to policy makers, service providers, commissioners, frontline care staff and recipients
- **Dignity Map** as part of the Darzi NSR Support package and as part of the NHS Operating Framework supporting patient experience
- **NHS Constitution:** Explicit recognition that a world class NHS must give a new priority to dignity and respect for patients-Dignity at forefront of local work in response to NSR Implementation
- **Dignity Metrics** development- including local proxy measures for LAAs and Place-based initiatives

Your Care, Your Dignity, Our Promise



Elder abuse and dementia

- In a study of family carers of people with dementia, over 50% reported some sort of abusive behaviour toward their dependent, with verbal abuse the type most commonly reported

Cooper C et al. Abuse of people with dementia by family carers. British Medical Journal , 2009

Dignity in Elder Care and Dementia Services

National Dementia Strategy: February 09

- Improved public and professional attitudes and understanding of dementia
- Good quality health and social care from early diagnosis to the end of life
- Coherent care pathway for people with dementia and their families
- Further promote the voice of people with dementia and their family carers

How can we measure patient experience?

Patient recorded outcomes

Empathy Measures

Being with Patients Programme:

Patient Diaries

Patient Life Books

How can we commission for Dignity?

Paying for better quality outcomes and supporting providers

How can we link patient experience to broader social values?

Dementia Care Training

Avoid 'treachery' (tricks to gain compliance) , disempowerment, infantilisation, objectification. Dementia Care Quantum Training Manual. D.Walsh. 2006

Palliative care training and end of life care tools introduced to improve care at Risedale Estates. 5 homes with 243 elderly, infirm residents many dementia sufferers-Advanced care plan, issues around end of life, preferred place of care

Dementia Care, Dignity and Abuse Prevention

- Objective 1: Improved public and professional **awareness and understanding** of dementia
- Objective 2: Good quality **early diagnosis and intervention** for all

- Objective 3: Good quality **information** for those diagnosed with dementia and their carers
- Objective 4: Easy access to care, support and advice following diagnosis facilitated by a **dementia advisor**
- Objective 5: Structured **peer support and learning networks**
- Objective 6: Community **personal support** services
- Objective 7: Services within the **carers** strategy
- Objective 8: Good quality care within **general hospitals and intermediate care**
- Objective 9: Good **housing, housing-related and telecare** support
- Objective 10: High quality services within **care homes**
- Objective 11: Good **end of life care**
- Objective 12 : An **informed and effective workforce** across all services

Dignity: Ambassadorial Messages

- Key messages from Sir Michael Parkinson”
- •Local Leadership “ All that is required at the most is strong leadership and a couple of committed staff”
- •Small acts can make a big difference –“It was the little things that irked her, including being addressed in a loud voice when her hearing was perfect”
- •It is not rocket science –“common sense seemed to be missing”
- •Everyone’s responsibility –“we can all help drive up standards, whether that be by reporting bad care if we see it or by making sure we take time to show our appreciation when we witness someone going that extra mile”.
- •Meaningful activities –‘connecting with where people are!’ music and activities in care home sector
- •The power of Life Stories –get to know the person and let them not be defined by their age, gender, ethnicity, disability or condition.
- •Involve carers & families –make caring and support a real partnership

Measuring quality and dignity in health and social care

Six Quality Dimensions in Health and social Care

- **Safe**
Avoid risk of harm in receiving care, safeguarding people when vulnerable
- **A good experience for people**
Ensure dignity, respect, empowering people to exercise choice and control, involve people, families and carers in shaping services
- **Improving outcomes for people**
Ensure effective care with the right outcomes, integrated in meeting individual needs
- **Focus on healthy, independent living and quality of life**
Ensure independence and help people achieve the best possible health and quality of life
- **Access to services**
Appropriate, fair and timely access, planning services to reflect community need
- **Value for money**

How can Regulation Play a part in promoting Dignity and preventing abuse?

Embed Dignity in CQC / Healthwatch Assessments – dignity metrics

Provider Assessment/ Compliance Criteria- CQC to be assured of fitness for practice

New Enforcement Powers/ Risk Based Assessment

Commissioner Assessment

Co-production of regulations-making sense to those providing and receiving care (and their carers)

Lay Reviewers and 'Expert by Experience' input into inspection and review

Dignity Metrics

- National Nursing Review of Metrics and Practice
- Dignity in Care Metrics: Help the Aged/ Pickering Institute- framework of measures launched for use by care organisations
- Dignity Framework
- Essence of Care data
- Darzi Clinical Pathway dignity and quality findings
- Consolidation of Dignity Metrics: the respective roles of inspection and local management
- Performance Indicators in the NIS and PSAs
- Change the conversation around 'performance'- supporting service improvement or feeding the beast?
- Ensure that the Outcome Frameworks better support 'Putting People First' by linking outcome-focused performance to strategic aspirations
- Support a focus on particular areas most pertinent to the overall policy direction: Dignity and Quality



Dignity Northwest

- System alignment or joining up -North West
- □Delivering same-sex accommodation –major issue - working closely with NHS North West
- ●Three successful cross –regional events with other Northern regions on
 - –Dignity and End of Life Care,
 - –Dignity Who Cares –(an event targeted at strategic leaders) and
 - –Life Story Working (at which we launched the new Life Story Network <http://www.lifestorynetwork.org.uk/>)
- ●Closer alignment of the dignity with other key regional programmes: Commissioning, Safeguarding, Essence of Care, Workforce, Ageing Strategy, Dementia and Links through contributing and presenting at their respective regional events;

Dignity Northwest

- Engaging Leaders in the NW
- Direct engagement with all senior key leaders including:
- Directors of Adult Social Care, PCT Chief Executives, Chairs, Directors of Nursing and Clinical Governance, Chairs of OSC and Safeguarding Boards
- Requested that there is an identified lead Manager in each local economy who will be responsible for the co-ordination of work at this level
- High level 'Dignity -Who Cares?' event on July 1st 2009
- Attended by over 250 key local leaders across NHS and Social Care organisations
- Leaders at all levels -
- Increased the number of Dignity Champions by 345% from 580 to 2800
- Supported over 35 local events across the NW
- 9 of which were new Local Dignity Launch Campaigns led by Chief Executive / Director level leaders (Cumbria, Liverpool, Salford, Trafford, Stockport, Tameside, Halton, Knowsley and Lancashire)

Dignity Initiatives Northwest

- NHS Central and Eastern Cheshire
- •Dignity embedded in the Quality Section of the standard NHS contracts for main providers –acute, community and mental health
- •Providers will be performance managed against these standards through the formal contract monitoring meetings
- •The standards incorporate a number of components including:
 - –Patient/service user experience –how will the journey feel for patients/service users and families/carers
 - –Personalised care –will the service meet an individual’s need?
 - –Specific mention is made of providers ensuring services are delivered in line with the Dignity in Care Campaign, and ensuring all best practice guidance is used e.g. Hungry to be Heard, Age Concern.
- •Compliance (demonstrated through audit) against their Privacy and Dignity Policy.
- •Incentives through the Commissioning for Quality and Innovation (CQUIN) scheme

Dignity and Vulnerable Adult Protection in Oldham

- Oldham is progressing the Dignity Challenge agenda through the implementation of Safeguarding Adults.
- The development of the Policy & Training partnership sub-group, membership is made up of OMBC, Police, Health, Housing and other statutory & non-statutory agencies.
- Through the Policy & Training sub group a smaller working group is currently being developed to specifically work on the Dignity agenda and the Human Rights in Health care and make the links with other areas of work especially in Safeguarding Adults.
- Other areas to explore is the impact of Individualised budgets, ensuring that independence & individual choices are met to meet their needs and that their Dignity and respect is adhered to throughout.
- Work is under way collating data through Satisfaction Surveys that focus on Home Care.

Regional Award –Dignity Northwest

- Home Instead –winner of the NW Regional Award for Dignity 08/09
- •Focused on what really matters –personal outcomes
- •Allowing a husband carer time off to play golf
- •A very well educated lady
- •Very distressed at being wheeled in front of TV each day
- •Different carers caused particular issues
- •15 minute visits also causing confusion and distress
- •We found two Caregivers with a very similar backgrounds
- •Huge increase in her well being
- •A lady who was living in a nursing home
- •Very distressed at new surroundings
- •We brought her home and put in a combined care and tele-monitoring package
- •Hugely positive impact (and lower cost)

Dignity in Care Campaign- 2010 onward

- Recommendations from Independent Review of National Dignity Campaign
- •Clearer guidance on measuring and tracking patient experience would help those on the ground to effectively quantify and track impact;
- •Despite linkages between dignity and other DH policy work streams being made, this is an area that requires more focus and time;
- •In order to sustain and develop the Campaign in the future, regional and local stakeholders need to take ownership;
- •Campaign steering group –Voluntary sector stakeholders, Department of Health and SCIE web presence;
- •Successes of the Campaign need to be more proactively communicated to the public;
- •Recognising and emphasising the importance of staff being treated with dignity and respect by their employers. Boorman Report- 'Invisible Patients'.

Making Dignity and Zero Tolerance of Abuse sustainable

- Not just telling people –but connecting on an emotional level –**making dignity matter personally!**
- *What are our expectations / standards and what are some of the consequences –when and where we cross the line?”*

Dignity: A Social Movement?

- *"It might well be that the difference people make individually is a mere ripple on the surface of our care system, but each of those ripples added together create a wave, **a social movement and if this makes life better for some –then it has to be worthwhile.**"*
- *National Dignity Ambassador, Sir Michael Parkinson*