



How Do We Achieve Dignified and Compassionate Home Care?

Report on Community Consultation and Visioning Events

Report written by Andy Bradley, Frameworks 4 Change

Context

Commissioners in the new tri borough are developing new specifications and re tendering the care at home service with a view to new service arrangements commencing in October 2013.

The purpose of the consultation and visioning events was to gather the views of stakeholders who are directly affected by the care at home services and the way they are commissioned and provided. The events were attended by:-

- People who use the service
- Advocacy organisations
- Local Involvement network representatives
- Unpaid carers
- Paid carers
- Service Providers
- Commissioners
- Contract managers
- Health and Social Care professionals

The question at the heart of the events concerned the achievement of consistent dignity and compassion in home care. Both national (*Equalities and Human Rights Commission – Close to Home*) and local (*Local Involvement Networks and Advocacy Plus*) reports had raised significant concerns around the way in which care at home was being provided with a core theme being a lack of consistent dignity and compassion.

The consultation events followed a compassion based training programme in Westminster ('Everyone Matters') which has been well received with high levels of engagement from some of the local service providers and the LINK and some evidence of positive changes in attitude and approach from paid carers.

The 'Everyone Matters' programme is being offered in Hammersmith and Fulham and Kensington and Chelsea this autumn.

The Events

Four events were offered in June and July 2012

- June 29th Kensington Town Hall
- July 2nd Westminster City Hall
- July 5th Hammersmith Town Hall
- July 10th The Lighthouse

A total of 184 people attended the events:-

57 from provider organisations (31%)

69 professionals from health and social care (37.5%)

32 service users and family carers (17%)

26 from LINK and Advocacy (14%)

Purpose of this report

The purpose of the report is to analyse the data produced at the events and to draw conclusions and make recommendations based on the voices of people at the events in relation to the specification of future care at home services.

Purpose of the events:-

- **Consider compassion and dignity as a core requirement of service provision**
- **Develop a vision for good lives which include the care that people need**
- **Scope how services will be designed and delivered to support these good lives**
- **Develop a range of positive relationships with stakeholders**

Data gathering

Four questions were asked of all the people who attended the events:-

1. *When you need care, now or in the future, what quality do you most want in your carer?*
2. *What will always be important in your life, regardless of whether you receive care?*
3. *What is the most pressing challenge for care at home?*
4. *What can be done to achieve dignified and compassionate Care at Home so that people both receive the care they need and lead good lives?*

(In the final event question four was adapted as the group were asked to consider a point in the future in which they felt proud of the care at home in the tri borough and to imagine what had been done to achieve success: - *How do we achieve dignified and compassionate Care at Home so that people both receive the care they need and lead good lives?*)

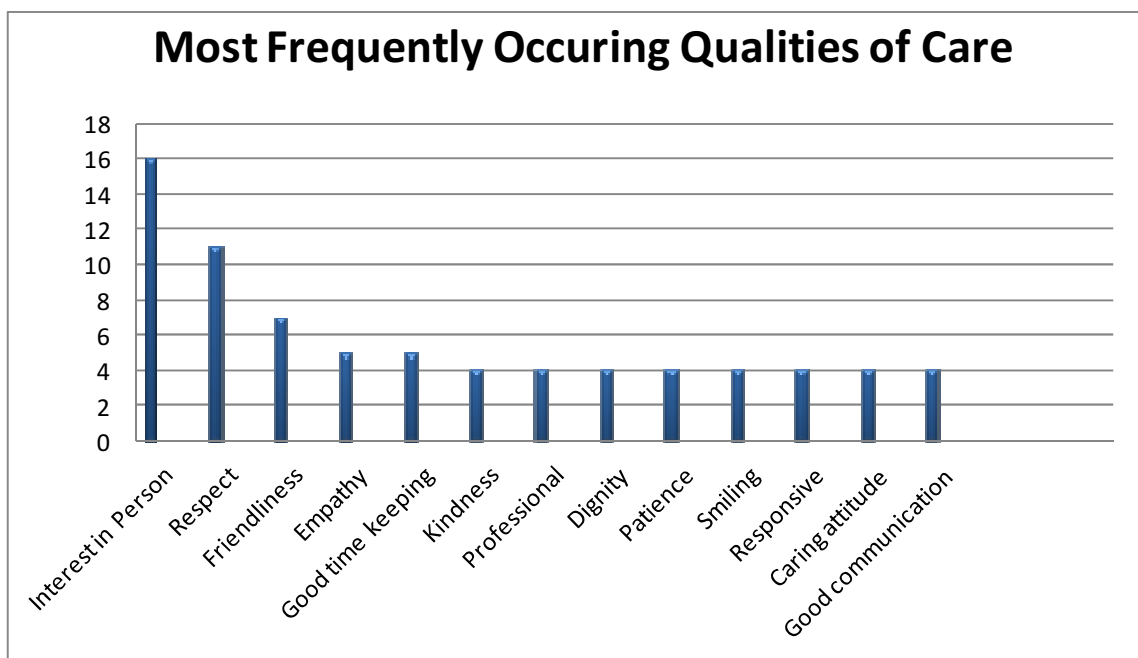
The Data

Question 1

When you need care, now or in the future, what quality do you most want in your carer?

43 Unique Qualities were identified in total.

The most frequently occurring are described in the table below:-



It is striking that the quality identified by the most people is about curiosity – the wish to be known; in policy terms this relates directly to the call for services to be personalised and directed by the person receiving the care. The curiosity of the care giver demonstrates respect and deep care.

Respect indicates a feeling of wishing to be seen and known as a person and not diminished by the experience of needing care.

Carers being on time matters to people as does a series of attributes and qualities that could be seen as features of a compassionate approach – put simply the people in the consultation wanted to feel that their carer wanted to be with them meaning that they would be smiling and friendly in manner, giving time, communicating well and being responsive to the needs and wishes of the person they were caring for – the development and monitoring of these qualities should be at the heart of recruitment and workforce development.

What this means for commissioners?

The report will go on to say more about the data and what it means but retaining a sharp sense of what matters to people who receive care is a core element of commissioning for dignified and compassionate home care. Compassion training locally has been shown to make an impact on qualities of care offered and the national and local work on dignity has been significant in placing value on the 'way of caring'. The qualities listed above suggest that commissioners should expect providers to ensure training is integral to care worker development in some of the most basic of human transactional skills including listening skills, empathy, communicating effectively and problem solving.

In addition to the values that were important to people, some also highlighted the fundamental importance of care workers possessing basic skills in order to be able to offer 'tea and toast' (and other more complex everyday tasks) to people needing care.

Commissioners should also consider the issues for receivers of care around professional boundaries as many people at the consultations were asking for smiles and friendliness; how do commissioners create the conditions for care workers to reveal their humanity and individuality? – being explicit in the commissioning and contracting that these qualities are essential in service provision may go some way to changing the culture from one which runs the risk of being dehumanising and mechanistic to one in which compassion and dignity for all concerned is at the heart of the way care at home is provided.

Question 2:-

What will always be important in your life, regardless of whether you receive care?

Item	Frequency	Quotes
Family and friends	89	<i>To keep my relationships with my loved ones, family and friends To have the love and proximity of friends and family Maintaining relationships with family without them taking on a caring role for me Feel part of the family rather than isolated Ability to connect to the people who mean most to me</i>
Independence	37	<i>I do not want to end up in a care home I would like to be as independent as much as I can Being able to lead the life I want with or without help</i>
To be listened to and to be known and valued	35	<i>...be able to be an individual To be treated as an individual Valued for the person I am I am a person with a history</i>
Being in control of choices	35	<i>Feeling myself and to be in control of my life</i>
Respect and dignity	34	<i>I like to give respect and therefore like to receive the same</i>
Health	29	<i>To feel comfortable, healthy and not in pain</i>
Pursue interests, learning and hobbies	28	<i>To be busy – not to have to think how to fill my waking hours Maintaining my lifelong personal interests</i>
Being part of the community	19	<i>To keep in touch with the world... Help others</i>

This question invited the delegates at the events to think beyond the need for care to consider what continues to matter to them regardless of their need for care now or in the future. The dynamics created when care giving in people's homes can lead to a loss of focus on the individuality and wholeness of people requiring care and people can be diminished in the minds of others as a result – the challenge in giving care is to remain aware not only of the care needs of the person being cared for but also as the person as a whole human being.

The data for this question is dominated by the first value with just under a quarter of all respondents saying that **family and friends** will always matter regardless of the need for care – this suggests a clear imperative on services to work alongside people receiving care and their families wherever possible. Commissioners should be mindful of the crucial role the families and friendship networks play in the lives of many people requiring paid care at home and should ask providers to demonstrate the ways in which they will work with these networks as full partners in the development of care and support that is right for each person. In many cases the provider will be working alongside unpaid carers (in nearly all cases a loved one) – commissioners should ask providers to develop approaches which demonstrate respect for detailed joint working with unpaid carers. Some comments were made at the events re how difficult it can be for unpaid carers to trust

paid carers – skills in empathy, listening and communication are again key to developing the care at home that people want.

Independence was important to a significant number of the group with a feeling that remaining at home with the right care and support and avoiding a move to a care home and or hospital admissions was of great importance.

Being listened to and known mirrors the quality of care highlighted in the first question – curiosity. People who are at a point in their lives where they require paid care should not be defined by their need for care but instead are a sum of all of the elements of their lives; their values, cultural identity, history, relationships, sense of place and plans for the future.

Being in control and making choices is in alignment with the national direction of travel on policy which says that services should be personalised and led by people receiving services so that care is part of a good life and people requiring care remain in control of their lives.

Respect and Dignity lie at the heart of the consultation on care at home and are centrally important to people requiring care – a sense for the person that they matter and that the person caring is respectful in their approach are fundamental elements for commissioners and should be at the front of their minds in developing specifications and working with contract teams and providers to set the highest standards for respect and dignity in care at home.

Health – *is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity**– people who require care at home continue to have the potential to flourish and should expect the best that an integrated health and social care system has to offer.

(* from preamble to the constitution of the World Health Organisation – 1946)

Pursue interests and hobbies and being part of the community– remaining motivated and interested in life is key to continuing social connections and valued relationships. Having a need for care does not, by definition reduce the sense in which people need to belong and contribute, if anything this need may be heightened as the belonging that comes through employment or other associations may become more difficult to sustain.

Conclusion

Combining the qualities of care that people at the events said matter most (curiosity came first) with the ‘what will always be important in your life’ question (families and friends is leading answer) leads to the conclusion that participation, contribution, connection and well-being should lie at the heart of commissioners thinking about the kinds of services that people want when they require care in their homes. A compassionate approach calls for us to consider both the ways that people suffer and what enables them to flourish.

Having analysed and drawn conclusions on what matters most to people in the commissioning and design of care at home, the report now turns its attention towards the current challenges and solutions required to achieve the kind of care at home that people are asking for.

Questions three and four invited the participants at the events to first reflect on the key challenges in providing care at home and then to think about what can be done to create consistently compassionate and dignified care at home.

The questions:-

3. *What is the most pressing challenge for care at home?*
4. *What can be done to achieve dignified and compassionate Care at Home so that people both receive the care they need and lead good lives?*

Five consistent themes emerged:-

1. Service User Leadership and Control (self-directed support)
2. Workforce Development (values, quality and consistency)
3. Culture Change (humanity and compassion)
4. Service Design (flexibility, simplicity and integration)
5. Radical thinking (asset based and community connecting)

The data is presented below in relation to these themes with each highlighting:-

- Challenges
- Solutions
- What this means for commissioners

Please note* - Words in italics are quotes from people who attended the events

THEME 1: SERVICE USER LEADERSHIP AND CONTROL

CHALLENGES

- Lack of Individuality of the Service
- Personalisation and direct payments not implemented fully
- Relationship with family members often not at the heart of the care
- Poor communication between service users, professionals and support providers
- Assessment – conflicting information, duplication and ignorance of service user needs....practice seems to be poor and inconsistent
- Lack of person centred thinking – whole purpose of the service should be to understand and be led by each individual

*'The individual, working out what they want, working it out for themselves, freedom to choose'
'Flexibility, choice and control has been taken away; not providing care will cost money in the long run and have effect on health. Someone to talk to about direct payments when I have a problem'
'Recipients of care are employers, effectively carers work for them – they shouldn't be dictated to'*

SOLUTIONS

*'That when I have problems with my direct payments someone is here to support and help me'
'Empowering people to do own assessment, own support plans and to ensure people to access independent support if unable to do so themselves.'
'Very important for SU to meet carers and develop relationships'
'Person is expert in their own life'
'Fully implement the self-directed support agenda'
'To get holistic approach - community, families'
'To decide what will matter at the end of life - must know next of kin'
'Service users to choice own carers'
'Complaints about carers should be taken seriously'
'Paid carer to work with family'
'Listen, support, and take on-board complaints'
'Assessment – should be independent of those who provide the service'
'Family as equal members of team and working to achieve same outcome'
'Awareness of life styles'
'Choices and voices to be heard. Individualised to need'*

WHAT THIS MEANS FOR COMMISSIONERS

1. The full implementation of self-directed support should lie at the heart of commissioning for care at home
2. Effective co-production partnerships with user led groups (including advocacy organisations) are integral in creating the conditions for effective self-directed support
3. Commissioners should be vigilant about respect for unpaid carers and involvement of family and friendship networks in creating the conditions for people to both receive the care that need and lead good lives
4. A citizen led model which incorporates rights, equality, inclusion and independence should inform the way care at home is commissioned

THEME 2: WORKFORCE DEVELOPMENT (VALUES, QUALITY AND CONSISTENCY)

CHALLENGES

- Inadequate Training for Staff
- Poor Pay
- Lack of continuity and consistency (examples of many different carers for each individual)
- Lack of autonomy for the carers – lacking empowerment to make flexible decisions
- Lack of accountability of agencies for quality of service – putting things right when they go wrong, consistency in quality of caring
- Lack of knowledge and education re cultural diversity of people being cared for – customs, food, beliefs and values not sufficiently well understood
- Recruitment – developing a robust recruitment and selection
- Lack of routine support and supervision for paid carer

‘Carers needs not understood, carers told what to do’

‘Agencies in it for the money - £7 for carer, £7 for agency – needs a different way of organising’

‘Partnership, in hard times it is easy to blame others – work together to achieve aims’

‘Carers need to understand the individual – it is not about the care plan’

SOLUTIONS

‘Training and supervision for carers and recognition’

‘Diversity very important - respect other cultures’

‘Teach carers to have the right attitude’

‘Carers being praised and thanked when they are doing well’

‘Dignity and compassion at heart’

‘Carers need supervision - they are working under pressure and task orientated’

WHAT THIS MEANS FOR COMMISSIONERS

1. Commissioners should expect consistently compassionate and dignified care and support
2. Commissioners should work with providers to develop high quality and innovative approaches to workforce development (including recruitment and selection, training, mentoring and supervision)
3. Commissioners should see high quality and inspiring leadership as integral to offering consistently compassionate and dignified care at home
4. Commissioners should reflect on the terms and working conditions of frontline care workers and should be attentive about ensuring terms and conditions are valuing and respectful
5. Commissioners should expect providers to develop and implement specific and on-going strategies for workforce well-being in recognition of the challenges to workers who are often isolated and working in complex and demanding situations.
6. Commissioners should specify that rights and equalities are core to providing the best care at home – people who receive care should be confident that their individuality will be respected by care workers who are educated and knowledgeable regarding cultural and personal identity
7. Commissioners should expect that service providers ensure all care workers possess basic skills, which are integral to everyday living.

THEME 3: CULTURE CHANGE (HUMANITY AND COMPASSION)

CHALLENGES

- Recruiting people who value the job
- Care Work not a profession – low status and it is devalued
- Dehumanising care makes people feel like giving up – need compassion and dignity
- Care Work not a profession – low status and it is devalued
- Negative Perceptions of the Agencies – in it just for the money
- Societal views of care work are generally negative

'Agency owning the agenda – working out whatever the issue is – how do we deliver compassion and dignity'

'Not feeling valued'

'Move away from blame culture'

'Pay not relevant to compassion – look at certain qualities at interview stage'

'We have lost the art of compassion'

SOLUTIONS

'Being human - cultural change'

'Everyone has the same goal and ambition. Good communication. Rewarding good care, remove blame culture'

'Listen to staff complaints and concerns. Better benefits, realistic work load that is manageable'

'Work together as you would for a friend/family member'

'Carers can be friends; there can be appreciation on both sides'

'Courage to think outside the box'

'Put yourself in their shoes. Support the staff – agency'

'We can show appreciation to people'

'It is everybody's responsibility- a community response'

'Dignity and compassion embedded'

'Treating people as equals'

'Centre of excellence. Analysing good practice'

'Get rid of infrastructure and manage and give funding to service users, need good advocacy.'

Recognition of the experts. Would like to see money given to family, put family in control of their lives. Live lives according to own determination. Get away from the nanny state'

'Informal carers - formal carers and the cared for to be insured in care planning process as and when needed'

'Set bar high got people to lead good lives'

'More flexible, less rigid view of what care means - to help someone have good well-being. That my care is reviewed - when people see my mother (with dementia) let me know how she has been the last few months and have her needs changed?'

WHAT THIS MEANS FOR COMMISSIONERS

1. Commissioners should make sure dignity and compassion are at the core of care at home.
2. Commissioners should include all involved in care at home in a consistently compassionate approach (including themselves)

How Do We Achieve Dignified and Compassionate Home Care:

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3. Commissioners should develop approaches to monitoring quality which enable users and care workers to describe their experience in the context of dignity and compassion
4. Commissioners should ensure a fully integrated approach is taken across health and social care
5. Commissioners should create the conditions in which providers are effectively 'competing on compassion' (for example through contracting and monitoring)

THEME 4: SERVICE DESIGN (FLEXIBILITY, SIMPLICITY AND INTEGRATION)

CHALLENGES

- Lack of Time when people are giving the care
- No way of rating agencies on best practice – no system for finding the best one in your area
- Patching – time constraints on carers for travel
- Travel – time and not paid travel expenses
- Lack of Punctuality of carers
- Re-ablement is time limited when it may need to be on-going
- Matching of carers to recipients
- Lack of flexibility of care plans – even though needs change regularly
- Complaints procedures – service users seem shy of complaining for fear of reprisals

'Needs to be time for what is important to 'me' – at a particular time'

'Two sides to prevention – enablement and cost'

'Concerns that care managers do not have enough time to assess for care at home'

'Point of prevention is to prevent unhelpful care'

SOLUTIONS

'Create market for people to use personal budgets well'

'Prevention – asses well what person needs – if system is good, outcome will be positive'

'Extend enablement (shouldn't all care at home be enabling?)'

'More flexibility in approaches throughout care planning. Increasing agency capacity - match carers to person. '

'Every service user has an allocated worker who will have links with all relevant people and meet frequently'

'Further integration between health and social care'

'Motivate properly - if not be dismissed'

'Simplify bureaucracy and put resource into front line services'

'Carers on time'

'I like Martins idea of Trip Advisor way of choosing agency/carer'

'Worker expenses must be paid'

'Travel time should be paid'

'Outcomes, not time and task'

'Social inclusion/prevention'

'People who train carers - managers/admin don't know what's going on. They should shadow carers and see what's involved'

'Publicising success stories'

'Knowing what's on in the local community'

'Patching, being part of a local community'

'Carers set the schedule. Carers making more decisions about the care service. More input on continuous planning authorise more hours'

'Flexible to support people not written in stone – flexibility'

'What outcomes people want to achieve'

'Change name of home care'

'Monitoring of personal budgets and direct payments to be more frequent and social services to remain involved'

'Focus of care linked to strength and desires'

'Maintain continuity of carers. Constancy. Create friendships. 3 visits from same carer per day! Ideal, lovely'

'Joining up budgets - make money available. Discharge should start at hospital as soon as person comes into hospital and community charge'

'Need for flexibility example of SU in wheelchair who wants to go out for a walk with carer instead of them doing housework. At start of service sus should be asked what flexibility they would like'

'People meet to design service together, look at where it is working & replicate'

'Help with transport - bus passes. Using technology to enable carers and SU's to be closely connected'

'Provide more money for the individual - will save in the long run'

WHAT THIS MEANS FOR COMMISSIONERS

1. Commissioners should ensure providers are working within a locality neighbourhood model to increase consistency and knowledge of local communities – where possible care workers should work as teams with supervisory and mentoring support to support service users and each other
2. Commissioners across health and social care should work with care managers and contract managers to simplify assessment processes so that duplication is avoided and flexibility for the service user is maximised
3. Commissioners should create the conditions where resources can be used with a degree of flexibility to meet service user needs
4. Commissioners should consider a strengths based approach which assesses and mobilises assets and builds resilience so that service users do not become overly dependent on service provision
5. Commissioners should be aware of the implications of Health and Well Being boards in the context of commissioning for dignified and compassionate care at home
6. Commissioners should work closely with safeguarding leaders to ensure robust mechanisms are in place
7. Commissioners should expect providers to develop effective mechanisms for on-going feedback from service users (including both complaints and positive recognition) which leads to plans for continuous improvements to be made and acted on

THEME 5: RADICAL THINKING (ASSET BASED AND COMMUNITY CONNECTING)

CHALLENGES

There is a general challenge inherent in the consultation which acknowledges that the current arrangements for commissioning and provision of care at home make ensuring consistent dignity and compassion impossible.

SOLUTIONS

'Employers including councils pay into pensions/life insurance to provide home care to help out social services. Businesses and LTD companies should put money aside for this'

'The transport for all idea of issuing freedom passes to carers would make a massive difference'

'Role within voluntary sector red cross - take to shops - give time'

'Little money in LA's think community solutions'

'Care in return for care (exchange programme)'

'Look at other countries and cultures and how they deliver care. Learn from others especially Japan'"KOREIKYO"'

WHAT THIS MEANS FOR COMMISSIONERS

1. Commissioners should recognise the deep challenges and complexities in developing consistently compassionate and dignified care at home and should invest in a period of further research and reflection to inform their thinking.
2. Commissioners should recognise the need for radical thinking in relation to both the data from the consultation and the major changes being called for in the way health and social care is provided.
3. Commissioners should consider the value of innovation and consider setting aside resources to incentivise small scale pilots of alternative asset based approaches to care at home.
4. Commissioners have demonstrated a willingness to invest in asking deep questions about dignity and compassion and to offer compassion based programmes of learning – this commitment now needs to continue to develop services which are in line with these values.

Discussion and National Development Work

The New Economics Foundation identify five ways to Well Being (see links below) and highlight 'keep learning' as key to continuing flourishing and well-being. People who require care at home run the risk of becoming socially isolated and lonely which may lead to further health challenges around mental health and well-being. Commissioners should consider how they can create the conditions for 'outward facing, asset based' care at home which, as well as offering the care that people need are also connected to the community through a range of formal and informal partnerships.

<http://www.neweconomics.org/projects/five-ways-well-being>

Asset Based Community Development is concerned with identifying and building on the strengths that often lie dormant within communities –this thinking asks commissioners to create the kinds of services that release social capital within individuals, families and neighbourhoods so that services offered sit alongside the informal networks and associations that are pre-existing in all communities.

Shared Lives and partners produced a report on the kinds of values and behaviours within councils that create the conditions for personalised asset based solutions to thrive and have identified 'seven principles for inclusion and empowerment in an age of austerity':-

The report sets out seven principles for empowerment and inclusion in an age of austerity:

1. Community development needs to start from how people themselves define their situation and aspirations.
2. Communities are stronger where people who use services are helped to find good ways of making a valued local contribution, not just seen as in need.
3. Most support is delivered by families and social networks: services must work in partnership with those whose contribution is unpaid.
4. The personalisation of public services marks a genuine change when it represents a change in culture, aspirations and choice of providers.
5. To live fully, we all need to be able to make informed choices and to take risks.
6. Public sector contributions are more cost-effective when they look across all local assets and needs, not just at those assessed as 'most needy'.
7. Micro-scale enterprises and interventions can be a powerful vehicle for mobilising new contributions.

See their report here – <http://sharedlivesplus.invisionzone.com/index.php?/files/file/39-creating-stronger-and-more-inclusive-communities-which-value-everyone%E2%80%99s-right-to-contribute/>

Helen Sanderson Associates and the Think Local, Act Personal (TLAP) partnership have joined forces to consider the integration of personalisation, person centred thinking and a focus on outcomes in the development of the kinds of support people want as part of a good life. The 'Progress for

Providers' framework developed for a care home in Stockport has been very well received nationally and may offer a schema for commissioners of care at home to consider what 'getting it right' looks like from perspectives of all involved in care at home. Work is now underway by Helen Sanderson and TLAP to develop this thinking in the context of care at home in the North West.

See 'Progress for Providers' here -

<http://www.helensandersonassociates.co.uk/media/75875/progressforprovidersdementia.pdf>

The factors identified above by stakeholders at the consultation events call on commissioners to make a fundamental shift in thinking and practice in commissioning care at home services. Changing the culture in health and social care is complex and daunting but it may be that the current context with a renewed emphasis on health and social care integration and the deeply challenging financial context creates the conditions for radical new thinking which is focused on sustaining the well-being of people who require care (and critically those who provide it). A continuous emphasis on well-being and compassion may create the conditions where people both receive the care they need and continue to lead good lives.

Learning directly from the experiences of pioneers in the fields of self-directed support, micro enterprise, inclusion, person centred thinking and asset based development may give commissioners the insight and intelligence needed to successfully make this paradigm shift.

Organisations with relevant experience and expertise:-

Centre for Welfare Reform

Shared Lives

Community Catalysts

Centre for Inclusive Futures

Nurture Development

New Economics Foundation

Think Local, Act Personal

Helen Sanderson Associates

What next?

To build on the success of the consultation process and the work already underway to place compassion at the heart of care at home commissioners may wish to consider a next 'co-design' phase which brings together local stakeholders with the national relevant experience of asset based thinking to develop and pilot the radical solutions needed to provide care at home which rises to the challenges posed by both senior tri borough leaders and advocacy and LINK representatives.

This report will be shared with all who attended the consultation events.

Commissioners will reflect on this report and the data captured of what was said by all of the people who attended the events.

- June/July 2012 Initial consultation events
- August-September - collate all findings; look at best practice examples; draft specification; scope
- October –November 2012 - finalize specification/service modeling; agree governance authority for each borough
- December 2012 - tender process starts
- End September/beg October 2013 - award framework/contract
- October 2013 - implementation begins

Commissioners will consider how best to respond to the data and recommendations and will consider a co-design stage with a smaller group of stakeholders to develop the detail of how care at home services will be commissioned.

Comments on this report and on any other aspect of the development of care at home services should in the first instance be emailed to:-

Christian.Markandu@lbhf.gov.uk