

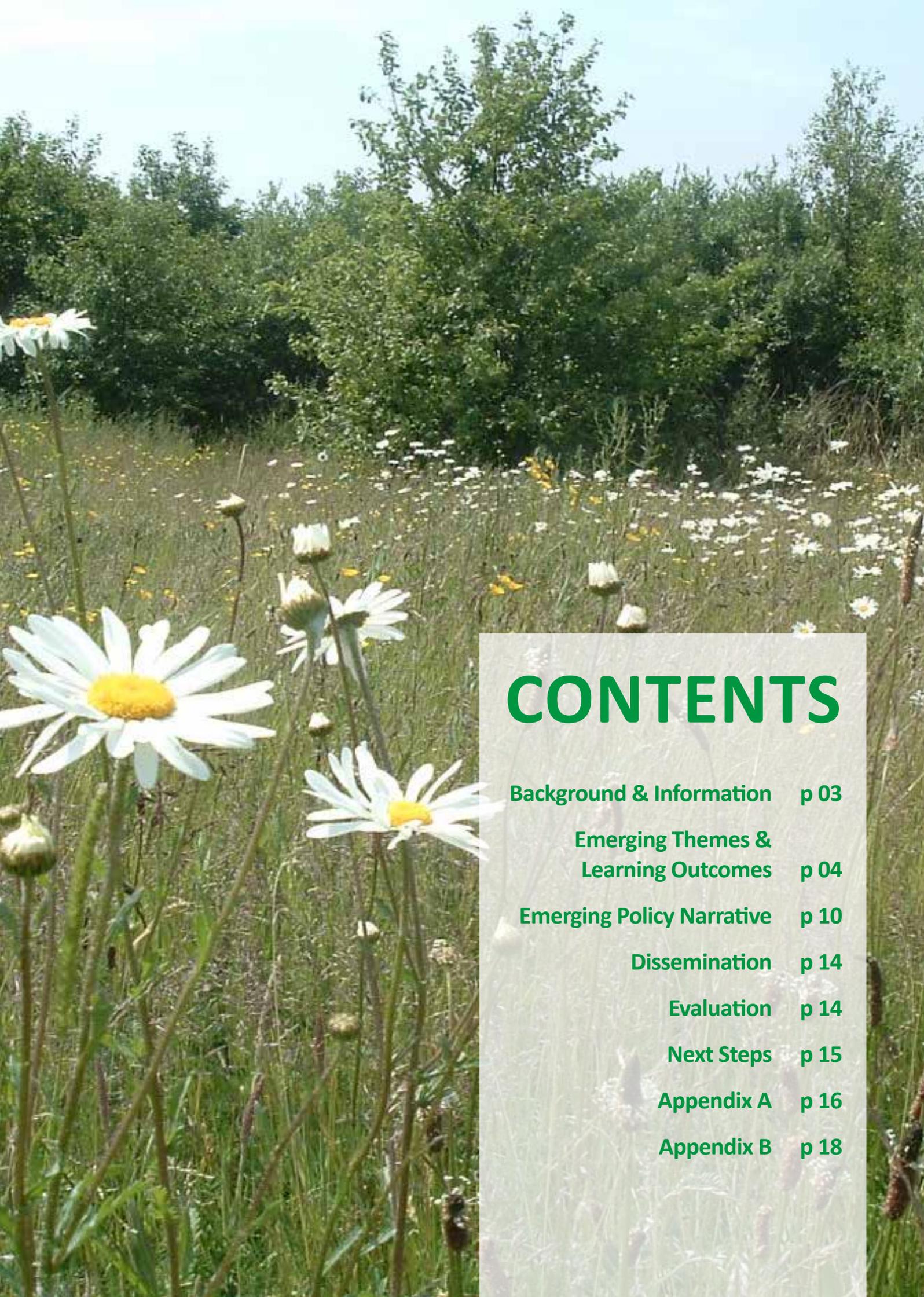


YOUR COMMUNITY MATTERS™

FINAL REPORT

JULY 2013

LIFESTORY
NETWORK



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Background & Introduction

Building on the successful delivery of the Your Story Matters (YSM) programme, also funded by the DH, we were invited by Martin Green (Chief Executive of ECCA) to join the Dementia Care and Support Compact, a response to the Prime Minister's challenge on dementia to work with care organisations to improve care and support for people with dementia and their families. Compact members have committed that their staff will deliver a personalised package of care and support, "by knowing the person, their life history and their personal culture" and will "play our part in supporting the wider community, sharing the knowledge and skills of our staff and inviting people into our care settings."

Our 'Your Community Matters (YCM) original project proposal to the Department of Health (DH) consisted of three bespoke elements:

Care Homes

'bringing the care home into the wider community' - building on the concept that care homes should be a focal part (hub) of the community, we wanted to facilitate members of the local community to become more engaged and involved by working with family carers and volunteers, including young people in education or who are unemployed;

Registered Social Landlords (RSLs)

'bringing together the wider community and creating dementia friendly communities' - using our approach to life story work as a vehicle, we wanted to facilitate and develop the capability and capacity of local communities to improve their support to people with dementia and families by working with family carers and volunteers, again including younger people;

Home Care Organisations

working through United Kingdom Home Care Association (UKHCA) we wanted to explore opportunities to work with a selection of home care organisations on a locality basis, building on the emerging developments in the 'Family Carers Matter' programme.

Based on our learning from the Your Story Matters project, we were keen to engage directly with organisations to secure strategic ownership of the cultural change central to the aims of the project. This proved somewhat more challenging than anticipated, which was probably reflected in the short timescale available for relationship building, effective communication, a reciprocal understanding of the needs of all three sectors and the impact and value of what we were offering. Notwithstanding this, given the learning needs of both the housing sector and home care sector in this area, they readily welcomed the opportunity to embrace this project and take up the available training.

We have trained 153 people in 11 organisations, as follows:

Organisation	Target	Achieved	Information
Sanctuary	45	36	Lack of demand from family carers for courses
MHA (3 homes)	45	21	Lack of demand from family carers and volunteers for courses
Housing Sector	40	74	High demand for staff, volunteers and family carers courses
Domiciliary Care	45	18	Lack of demand from family carers and volunteers for courses
Associate Trainers	0	4	
TOTAL TRAINED	175	153	87%



Emerging Themes and Learning Outcomes

Care Home Sector

The commitments of members of the Care and Support Compact included the intention to 'engage and involve the wider community to improve their support for people with dementia, including GPs and healthcare professionals' and to 'play our part in supporting the wider community, sharing the knowledge and skills of our staff and inviting people into our care settings.' The care providers we worked with have strong reputations for good quality dementia care and a willingness to embrace new ideas to improve what they do.

Their care home staff were positive and enthusiastic about the training we provided. Through this project we can demonstrate the value of working with managers and staff in care homes to use life story work as a way of ensuring relationship-based care and by knowing the unique biographies of individual residents better, to help keep them connected to their communities through activities that they enjoy, such as gardening, art or singing, or

through continued social interactions in their faith communities or at coffee mornings, lunch clubs and other local events.

Feedback from participants included:

"Made me realise that that I need to involve the residents more."

"This could help the integration of people with dementia instead of exclusion."

"Think about holding life story network awareness-raising days in the community."

"Life stories help with finding meaningful activities around which to communicate with the individual."

"Learning about human rights and how these are sometimes overlooked when dealing with people with dementia."

Whilst there was positive feedback from the participants about the use of life story work in enhancing the relationship between staff and individuals living with dementia, there was also some significant learning from this project about whether the aspiration in the Care and Support Compact that care homes should become the hub of their communities could indeed become a reality. From our observations and experience, together with feedback from care home managers, this aspiration may be difficult to realise fully on a practical basis, given that many of the care homes do not currently have the established networks into local communities. In the current economic climate with austerity measures impacting on current capacity, several of the care home managers reported that searching out other local organisations, societies and associations in the wider community and establishing and building relationships with them would require significant additional resources that are currently unavailable. This was disappointing for the LSN – but valuable feedback for national and local government and for care home sector representatives. Wider community engagement remains an important aspiration and a way of ensuring good care in addition to what happens inside the care home. Experience from this project suggests, however, that facilitating communities to engage with care homes, rather than vice-versa, may be a more effective approach in current circumstances.

Given these constraints, it was therefore not surprising that the care homes were unable to identify any volunteers from their local communities to participate in the training. One of the aims of working with this sector was to engage with young people as volunteers to interest them in the potential of social care as a career. However, the underdeveloped relationships of the care homes with their communities (in this instance) meant that this proved not to be possible. However, we fully believe that optimising the use of volunteering is an untapped resource in the local community with significant potential for stimulating interest in a growing health and care sector employment market, given the on-going challenges of recruiting high calibre staff into this sector. Indeed, through working with the housing sector, we were able to capitalise on some inter-generational work with young people and utilise this opportunity to connect with a local care home.

A key element of the YCM project was to work and support family carers in capturing and developing the life stories of the person being cared for. From

our previous project ‘Family Carers Matter (FCM), we know that involving family carers in this way empowers them in influencing and shaping the care and support provided as well as enabling them to retain their unique relationship with the individual person living with dementia. It is well documented that family carers should have a pivotal role to play in the ‘partnership’ of the caring relationship between individuals being cared for and paid carers. It was therefore a lost opportunity to find that the care homes in this project were unable to identify family carers or relatives, who could be involved in this project. The reasons for this are many and varied and lay outside the scope of this report to comment on.

Home Care Organisations

We anticipated at the start of this project that engaging with the home care sector would be difficult because of the logistics of releasing staff to attend training and the traditional restrictive nature of contracting with this sector (such as timed interventions which restrict the amount of contact time with individuals) that remains in place by many commissioners. The two home care providers that we worked with on Merseyside, however, proved to be responsive and enthusiastic about the offer of training in this area.

Feedback from the participants was both exciting and humbling; the most significant learning points included:

“How I can use this (life stories) in my workplace, lots of ideas, made me think differently.”

“That I know more than I thought I did and things you think are not so important really are.”

“How important it is to know the person, not the problem.”

“That people with dementia are still human beings with an illness.”

“I will be looking at changing my care planning systems.”

“It will enable me to give people a more person-centred care rather than use a medical model.”

Whilst we wait for the final report of the independent evaluation we suggest that the reasons for these transformational experiences may lie in the fact that although vocational awareness training supported by Skills for Care is on the increase, some home care staff may only receive mandatory or statutory training. What was offered in this instance was enhanced person-centred support and training. Notwithstanding the constraints in releasing home care staff for training, these home care workers enthusiastically engaged in this two day training programme in their own time.

As is illustrated by the above feedback, the content of this training was not only highly valued by individual participants but it also provided the opportunity for them to recognise, reflect and validate collectively the significance of their role in enabling people with dementia to live independently in their own homes. Furthermore, they are well placed to recognise the early signs of dementia in the people they support and the training gave them increased confidence to be able to advocate on their clients' behalf with family carers and with professionals.

With regards to engaging the home care sector to identify family carers and volunteers to be involved in this project, this was ambitious given the nature of their role. Home care workers often work in isolation and may have limited contact with family carers and relatives. At a time when the home care sector is receiving some negative press, it was refreshing and humbling to see first-hand the commitment, dedication and enthusiasm displayed by these individual carers. It was apparent from the participants that they were skilled at listening to obtain people's stories in their short interactions and understood that this was a way of providing better care for them. The home care staff also proved to be an invaluable link for people who did not have family carers at points of transition, such as admission to hospital or into residential care. This intelligence is often neither sought nor used, but can be crucial in providing continuity and understanding – an untapped resource in terms of integrated care. Working with this sector clearly impressed upon us that more investment in training and development for individual home care workers is required if we are to enhance and maintain the care and support delivered by them.



Registered Social Landlords (RSLs)

In our original proposal to the DH, we set out the potential role of Housing Associations (RSLs) in developing dementia friendly communities and our aspiration to explore how we might take this initiative further to build capacity directly at the heart of communities, spreading knowledge and skills beyond the health and social care sector. We aimed to build on our experience to date and apply our learning, as we continue to develop connections and establish relationships from the outside, by working with individuals at a community level involving family carers and inspired volunteers.

This was new territory for us and we anticipated spending considerable time in developing the necessary relationships. This proved to be the case but our efforts quickly bore fruit. With help from the National Housing Federation (NHF) and through our own contacts we were able to approach RSLs on Merseyside, three of which expressed a strong interest in participating in the project.

The lack of up-take in the training places in relation to family carers and volunteers in the home care and care home elements of the project meant that we were able to extend the housing element, resulting in our delivering training to 74 participants against our target of 40 for this sector. We revised the content of our training, after consultation with the local housing providers, to ensure that it was more bespoke and resonated with those in the housing sector.

We adapted the course for volunteers to meet the needs of staff with little knowledge of dementia, refocusing it to incorporate an element of dementia awareness in the context of getting to know and understand the individual through capturing and using life stories to establish and develop relationships with individuals and families. Overall these courses for volunteers and staff were incredibly well received and were over-subscribed, indicating a clear demand for further training in this area. Feedback from volunteers and community representatives was very positive: There is often a fear of dementia and a lack of confidence in how to communicate:

"I found it an amazing experience and feel much better equipped to offer my help and support to anyone with dementia in the future."

"Wider understanding of both dementia and life stories."

"Life stories encourage people to listen to evoke memories, make things more accessible and encourage communication."

"Putting issues around dementia into context and I am feeling more confident in how to approach a person with dementia."

"My understanding of dementia is much improved."

"This training helps with ensuring that the wider community has a better understanding about the issues people with dementia face and that they have interesting back stories to tell, that may have similarities with our own."

"Want to get the life story message across to as many community groups as possible so that they too can get involved."

"I now have confidence to have conversations with old people!"

We have a track record of delivering volunteer training as a key partner in the Everton in the Community (EiTC) dementia project 'Pass on the Memories'. We have used this approach to ensure that we build on our experience to date, apply our learning as we continue to develop the volunteer programme for the housing and community sector so as to establish a common platform of understanding about dementia and value of inclusive age-friendly communities. The following contribution from the Liverpool Housing Trust (LHT) confirms the value of this approach:

"LHT fully support the work that LSN are doing to raise awareness of dementia and the benefits of life story work when supporting someone with the illness."

"We do not provide hands on support ourselves or personal care services but our scheme managers are often the first to identify when someone is ill or not managing in some way or other. Sometimes the first time we are made aware of someone's illness is through a change in behaviour which can be construed by others living at the scheme as anti-social."

LSN have delivered training sessions to groups of our tenant volunteers who will be spreading the awareness with their neighbours, and to groups of family carers. Both of these courses have been really well received with attendees reporting to me that they have really enjoyed the training and that they feel they have a much greater understanding of the disease as a result. The training has been well planned and pitched at the right level."

The RSLs involved recognise the importance of ensuring that they are responsive to the needs of people with dementia and their family carers who live in general housing stock, not just those in specialist extra-care or sheltered housing schemes. One particularly valuable session was with tenants, some of whom had personal experience of dementia through family or friends but many of whom wanted to know more about dementia so they could challenge the unsympathetic and often hostile attitudes of fellow tenants towards their neighbours who had developed the illness. A major learning point from the project, therefore, is the potential of the housing sector to play a pivotal role in the development of inclusive age- and dementia-friendly communities.

Although the difficulties in engaging volunteers meant we could not realise fully our ambition to work with young unemployed people, our developing links with the housing sector, in this instance South Liverpool Housing (SLH), opened up the opportunity to provide a session on dementia awareness and life story work in Parklands High School in Liverpool, involving young people who were at risk of exclusion from mainstream education. Their teacher had already organised for them to do voluntary work in a local care home and this training gave them additional knowledge and practical skills to use with residents. It is now planned that they will incorporate life story work into the regular weekly session organised between students and residents.

The training was very well received by the young people involved; they were engaged and interested and one young woman said it was the most she had written all week! It contributed to inspiring another young woman to accept an apprenticeship in social care rather than pursue her stated ambition to become a hairdresser. The school is keen to extend this project; they can readily see the benefits of their involvement, not only in connecting the students with older residents in the community, but more

importantly it provides the students with the opportunity to develop inter-personal and communication skills, with a view to pursuing careers in the health and social care market. The following are some of their comments about the day:

"The videos were heart catching and made me have a better understanding about the needs that have to be met for my grandad as he has got vascular dementia"

"Realising what memories mean to people and families, bring such happiness"

"Learning that you shouldn't stereotype people with dementia"

"The fact something so small can bring back so many memories to a person"

"Knowing a lot of new things, like about elderly and what they are like"

In the context of our learning from our work with the housing sector and to support its ongoing development, we have been working with the National Housing Federation (NHF) and the Housing LIN to explore the possibility of an action learning set to share good practice, provide peer support and develop case studies.

Our Offer...

- An Interactive Network - Individuals and organisations keen to offer peer support, exchange ideas and spread the message
- Local Networks - Supporting the creation of local LSN networks.
- Your Story Matters - Learning for individuals and groups in the practicalities of life story work.
- Family Carers Matter - Learning opportunities in life story work, developed specifically for family carers
- Your Community Matters - Bringing together housing and residents to better understand and improve their environment





Emerging Policy Narrative

The Final report of the Mid Staffordshire NHS Foundation Trust Public Inquiry

Since this project began in December, the policy landscape and national narrative have changed against the backcloth of the final report of the Mid Staffordshire NHS Foundation Trust Public Inquiry, continuing and increasing pressures on acute services, a renewed call for an integrated approach across the whole care system and the return of public health to local authorities, bringing a sharper focus on their role of delivering improved outcomes for local people through Health and Well Being Boards.

The Francis Report spans three volumes and has 290 recommendations. It builds on the work of an earlier independent inquiry by Robert Francis QC, which was published in 2010, and the Healthcare Commission investigation into care at the hospital. The final report argues that to improve care the focus should be on changing cultures not changing systems. It also argues that patients should be at the heart of the healthcare system and that patients and the public should be listened to.

Specifically, it calls for a radical shift in culture across the health care system, where openness and transparency will be underpinned by a statutory duty of candour. It calls for a stronger emphasis on effective meaningful relationships with individuals, families and the public as the basis of high quality compassionate care.

Compassion in Practice

The focus on relationship based care was also echoed in the new strategy for nursing, midwifery and care givers working across the whole care system. This strategy highlighted necessary core values which need to underpin excellent care and support for all people. These values have become known as the 6Cs: care, compassion, competence, communication, courage & commitment.

The delivery of the 6C's has been underpinned by six areas of action including:

- Helping people to stay independent, maximising well-being and improving health outcomes
- Working with people to provide a positive experience of care, delivering high quality care, measuring the impact of care, building and strengthening leadership
- Ensuring that we have the right staff, with the right skills, in the right place
- Supporting positive staff experience

Dementia – Finding Housing Solutions

This recent report published by the NHF (May 2013) highlights the pivotal role which housing organisations play in providing the infrastructure, services and wider community relationships that allow people with dementia to carry on leading their lives, as part of the community, in their own homes. Housing staff are extremely well rooted in their local communities and command a high degree of trust and respect among their own tenants as well as with other local care and support networks. With the appropriate training and support, front line housing staff are well placed to provide face to face health checks, spot the early signs of dementia in individuals, and provide information and advice about local services. They can reduce the potential of social isolation and loneliness felt by many individuals with dementia and their families, and instead promote a sense of community, continuity and inclusivity by harnessing and brokering more meaningful relationships and social connections among residents and the wider community.

The report provides a number of case studies and highlights the significant benefits of working more closely with the housing sector for all parts of the care system.

Specifically it highlights that working with housing organisations and floating support services can have the following positive impact:

- Reduce placements to care homes by 28%
- Help design more home-based solutions which will reduce pressures on the whole care system and specifically the hospital and care home sectors
- Facilitate early discharge and managed re-admission, reducing the overall length of stay in hospitals

- Reduce social isolation by enabling people to remain connected in their own communities

The report highlights that integrating housing into the dementia care pathway can deliver better outcomes, better value for money and help meet the aspirations of those living with dementia.

Integrated Care and Support: Our Shared Commitment

In May 2013, 14 national organisations (including ADASS, CQC, LGA, Monitor, NHS England, HE England, NICE, PH England, SCIE TLAP, and National Voices) signed the concordat 'Integrated Care and Support: Our Shared Commitment'. By establishing this commitment, they are sending a clear message that we need to have a much "more integrated approach across the entire health and social care system" (p.6).

It argues that integrated care and support are a means to an end and that efforts should be targeted at 'improving the experiences and outcomes of individuals and communities, whilst allowing people to become true partners in their own care and support' (p.13). To this end, they asked for a new narrative to be designed, such that an individual person would recognise integrated care and support. National Voices defined it as follows:

The Narrative

"I can plan my care with people who work together to understand me and my carer(s), allow control, and bring together services to achieve the outcomes important to me."

National Voices (p.15)

This narrative has been endorsed and accepted by all the key partners and is underpinned by a set of "I" statements, against which integrated care and support will be measured from the person's perspective (see Appendix A). Knowing what matters to people is central to the new narrative and listening to people's life experiences and stories is key to achieving this.

Of particular interest to us, given recent reports on the value of working with housing and in particular our experience and learning from the YCM project, is that although the emphasis is on a more integrated approach, there appears to have been no input to the concordat from any national housing partner (the Department of Communities and Local Government, Chartered Institute for Housing, National Housing Federation or the Housing LIN).

Outcome Based Approach – Focus on Well-Being

The three national outcome frameworks (NHS, Social Care and Public Health) provide a renewed impetus for local care partners to all work towards an ‘outcomes’ based approach, to support people living independently for as long as possible in their local communities. They should do this by putting in place preventative and early intervention strategies and reducing the current over-reliance on acute services at one end of the care continuum and residential / care home provision at the other. The recent announcement by Public Health England (6th June 2013) that they intend to rank all local authorities on their progress in meeting the public health outcomes will sharpen the focus on this approach. The NHF report ‘Dementia – Finding Housing Solutions’ calls for local commissioners (Local authorities and Clinical Commissioning Groups) to work closely with the housing sector and identify where costs build up in different parts of the system and redesign home-based solutions to relieve these pressures. This approach will support meeting the joint indicator in the NHS and Adult Social Care Outcomes Framework on the effectiveness of post-diagnostic care for people with dementia.





Implications for LSN

At LSN, we fully endorse the call for a radical shift in culture and leadership across our care system in the aftermath of the Francis Inquiry and the renewed focus on integrated care and support which improves outcomes for individuals and their families. We believe that there is an absolute need to refocus policy drivers, strategy, resources and organisational delivery systems from what are currently perpetuated: that is, an ill-ness service and supplier – driven (acute sector) system, rather than a well-being person centred system.

There is a wealth of evidence, both global and national, which supports a more integrated, community based well-being approach to enabling individuals to remain connected with their support networks where they live.

Our focus is to continue working on the nature and quality of relationships, which matter to individuals and their families where they live in their local communities. This approach puts a positive value on social relationships and local support networks, on self confidence and the ability of people to take control of their circumstances. This new model calls for us to enable and empower individuals, families and communities to refocus on their own assets and build their local resilience and capacity to address some of the issues relating to poor health and social isolation. Our integrated service response needs to scaffold and build on this – not replace it!

The emerging outcomes and learning from the YCM project powerfully illustrate that there are clear benefits in adopting this integrated whole community person centred approach, underpinned by the 6Cs and ensuring that there is a more central role for local housing organisations, working in partnership with the NHS and social care, to make this model work for all.

Dissemination

Members of the project advisory group have been invited to identify opportunities within their own organisations or in forums in which they operate for dissemination of the learning from the project. We expect them to include:

- News items and links to the report on websites;
- Contributions to internal workshops and conferences;
- Articles in internal newsletters and sector mailings;
- Presentations and workshops at sector wide conferences.



Evaluation

The independent evaluation of the YCM project is being undertaken by Social Care Can Do Partners. They are at the stage of follow up interviews with a range of course participants and we expect to receive their final report at the end of July. An early message is the confirmation that the quality of our training products and our delivery of the training are excellent.



Next Steps

The YCM project has confirmed the value of working with the care sector to promote relationship based care through capturing and using individuals' life stories, to improve the lived experience of people with dementia who use home care services or live in care homes. We will continue to promote this approach through our well established 'Your Story Matters' training for front line staff and by engaging with providers directly through our 'Leading Change Matters' programme. We are in dialogue with ECCA and the NCF about disseminating the learning outcomes for the care sector from the project.

The most significant learning from this project, however, comes from the invaluable insight and knowledge into the potential of local community working whilst engaging with the housing sector. Our learning has led us to understand the importance and value of the housing sector as a key facilitator and catalyst to deliver inclusive age-friendly communities. They are well placed to work across boundaries to develop partnerships and alliances to address the challenges of dementia. Housing Associations work to draw in diverse support for local communities and these skills could be used to reach out to the residential care setting too. There is an opportunity to build on work already started through the YCM project in respect of establishing dementia friendly communities, which we believe should be grasped and which the Department of Health may wish to support.

LSN have sown the seeds of this work across Merseyside with housing associations, schools, residential and homecare providers, health professionals, tenants and front line staff. We intend to connect these strands of work, to establish a community resource that can be sustained by volunteers and supported by established networks including housing providers and other key partners.

We are particularly keen to extend the work with young people as outlined in our original proposal, through our links with schools. We are in dialogue with our housing partners to scope out the potential and extend the work that has been already established and that will impact on the general health and wellbeing of individuals and the community as a whole.

As highlighted earlier, opportunities to develop age friendly and dementia friendly communities are recognised by UKHCA, NHF, CIH and Housing LIN. The NHF's recent publication "Dementia: Finding Housing Solutions" (May 2013) highlights a range of initiatives that have been taken by housing providers and demonstrates a pro-active approach to tackling now what will become a problem for them in the future. We are in discussion with the NHF and the Housing LIN about how we can build on these initiatives through a national network, to provide peer support to housing providers, develop practice guidelines and capture and disseminate further examples of good practice.

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John Shaw	Director	john@lifestorynetwork.org.uk

5th July 2013

Appendix A

Your Community Matters Advisory Group – Terms of Reference

Background

The Life Story Network CIC has been commissioned by the Department of Health under the workforce objective of the National Dementia Strategy to engage and deliver training to members of the Care and Support Compact and Housing Associations. The training will be delivered to 181 people that include:

- Senior/Middle Managers
- Front Line staff
- Family Carers
- Volunteers

Training will be achieved by a combination of group/team learning sets, reflective learning and constructive critique/feedback, together with an on line group space provision for sharing, supporting and networking within each organisational group. Additionally each group member will have access to the wider Life Story Network, on line forums, research information, resources and materials. The training will be delivered by LSN staff and their accredited Associate trainers. To support the project an advisory group has been established.

Role of the Advisory Group

The primary purpose of the group is to provide expertise and advice on the development and delivery of the training programme to ensure courses are appropriately tailored to each sector/group. The group will offer advice on the following:

- Content, scope of the training provision, including the alignment with developing Dementia Friendly Communities;
- Delivery methods/modes for the training;
- Engagement of the wider community;
- Ways to accredit, certify or endorse the training;
- Ways to disseminate learning from the project.
- Development of an effective community model within different settings

Members of the group will also be asked to:

- Facilitate access to their resources to support concept design and development of community educational resources
- Work with LSN's PR consultant to promote the project via website links, published articles, case studies, events and networking

Membership

The advisory group will consist of representatives from the following organisations:

NAME	DESIGNATION	ORGANISATION
Ruth Eley	Vice-Chair	Life Story Network
Anna Gaughan	Chief Executive / Programme Lead	Life Story Network
Pat Broster	Director & Project Manager	Life Story Network
Becky Sidwell	Policy lead – Dementia	Department of Health
Andrew Chidgey	Director of Policy	Alzheimers Society
Ken Clasper	Person living with dementia	Lewi-Bodies Society
Janice Clasper	Carer	United Carers UK
Deborah Sturdy	Consultant	ECCA
Jeremy Porteus	Director	Housing LIN
David Moore	Senior Lecturer	Worcester University Association of Dementia Studies
Amy Swan	Policy Officer	National Housing Federation
Peter Randall	Chief Executive	UKHCA
Kim Maslyn	Assistant Director, Leeds Adult Social Care	ADASS Older People's Network
Sharon Blackburn	Head of Policy and Communications	NCF
Larry Gardiner (corresponding member)	Person living with dementia	

Project Reporting/Meeting

Project updates will be via written reports and verbal updates at Advisory Group Meetings

30th January 2013

Written Report/ Meeting

28th February 2013

Written Report

20th March 2013

Written Report/Meeting (tbc)

17th July 2013

Evaluation Report/Meeting (tbc)

Appendix B

Box 8 . What integrated care and support looks like from an individual's perspective.

My goals/outcomes

All my needs as a person are assessed and taken into account.
My carer/family have their needs recognised and are given support to care for me.
I am supported to understand my choices and to set and achieve my goals.
Taken together, my care and support help me live the life I want to the best of my ability.

Communication

I tell my story once.
I am listened to about what works for me, in my life.
I am always kept informed about what the next steps will be.
The professionals involved with my care talk to each other. We all work as a team.
I always know who is coordinating my care.
I have one first point of contact. They understand both me and my condition(s). I can go to them with questions at any time.

Information

I have the information, and support to use it, that I need to make decisions and choices about my care and support.
I have information, and support to use it, that helps me manage my condition(s).
I can see my health and care records at any time. I can decide who to share them with. I can correct any mistakes in the information.
Information is given to me at the right times. It is appropriate to my condition and circumstances. It is provided in a way that I can understand .
I am told about the other services that are available to someone in my circumstances, including support organisations.
I am not left alone to make sense of information. I can meet/phone/email a professional when I need to ask more questions or discuss the options.

(...continued)

Box 8 (...continued). What integrated care and support looks like from an individual's perspective.

Decision making including budgets

I am as involved in discussions and decisions about my care, support and treatment as I want to be.

My family or carer is also involved in these decisions as much as I want them to be.

I have help to make informed choices if I need and want it.

I know the amount of money available to me for care and support needs, and I can determine how this is used (whether it's my own money, direct payment, or a 'personal budget' from the council or NHS).

I am able to get skilled advice to understand costs and make the best use of my budget.

I can get access to the money quickly without over-complicated procedures.

Care planning

I work with my team to agree a care and support plan.

I know what is in my care and support plan. I know what to do if things change or go wrong.

I have as much control of planning my care and support as I want.

I can decide the kind of support I need and how to receive it.

My care plan is clearly entered on my record .

I have regular reviews of my care and treatment, and of my care and support plan.

I have regular, comprehensive reviews of my medicines.

When something is planned, it happens.

I can plan ahead and stay in control in emergencies.

I have systems in place to get help at an early stage to avoid a crisis.

Transitions

When I use a new service, my care plan is known in advance and respected.

When I move between services or settings, there is a plan in place for what happens next.

I know in advance where I am going, what I will be provided with, and who will be my main point of professional contact.

I am given information about any medicines I take with me – their purpose, how to take them, potential side effects.

If I still need contact with previous services/professionals, this is made possible.

If I move across geographical boundaries I do not lose my entitlements to care and support.

"I statements"

The Person Narrative by National Voices



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