



Dementia and the Big Society

Report from Think Tank 16 February 2011

More than 40 people came together to participate in a Think Tank to consider the issues relating to living well with dementia and the Big Society.

A Think Tank is defined as a 'person or group of people, experts in some field, who are a source of ideas and who find solutions to a problem.'¹ In this instance the 'problem' is the exclusion of people with dementia from their communities, neighbourhoods and services across all sectors.

The Think Tank made no claims for putting the suggested solutions into action. It was, however, a vital first step in exploring the issues in the round and building a framework for the Big Society that will achieve inclusion for people with dementia.

The Coalition Government's 3 Big Society themes framed the discussions for the day as participants explored the opportunities and challenges in social action, community empowerment and public service reform. However, the Think Tank explored these themes from the perspective of politics with a 'small p'.

As groundwork for the Think Tank DH commissioned Innovations in Dementia to work with people with dementia in a rural area, a small town and an urban district to find out how they would define a 'dementia capable community'². A presentation of the findings from that work kick started the Think Tank.

Participants in the Think Tank included people with dementia and their supporters, community activists, providers of services across all sectors and academics (see annex a for attendance list). Prior to the event participants had read a Think Piece (see annex b) on Living Well with Dementia and the Big Society authored by Claire Goodchild and Simon Rippon who also conceived, planned and facilitated the event. A number of trigger presentations were provided throughout the Think Tank³ to offer some context and examples to the themed discussions.

This report is a summary of the discussions and ideas that emerged from the Think Tank. It does not necessarily reflect the ideas of the Department of Health, Alzheimer's Society and Bradford Dementia Group who lead Think Tank but we feel it reflects the contributions from Think Tank participants.

Summary: Key themes that emerged from the Think Tank

The 3 themes of the Big Society have much to offer people living with dementia.

¹ Chambers English Dictionary

² Dementia capable communities: the views of people with dementia and their supports

http://www.innovationsindementia.org.uk/projects_communities.htm

³ For all presentations see the homepage of www.dementia.dh.gov.uk

There is no singular solution to achieving inclusion for people with dementia. There are multiple solutions and all partners have a role to play in affecting change.

Empowering people with dementia, raising their expectations of their rights as citizens is a key step toward inclusion.

Relationships and power dynamics between people living with dementia, professionals and services are key to improving quality of services and assistance.

An assets based approach is vital to support and maintain people with dementia in their own networks, to avoid unnecessary dependence on services and to foster community development, inclusion and participation.

More conversations need to take place between people living with dementia, professionals, providers and wider society to reach a re-balancing of power and personal/community agency to promote more inclusion.

The 'art of conversations' was acknowledged as crucial for inspiring small changes that are as important as large scale change programmes

Key findings from the pre-Think Tank research with people with dementia

Innovations in dementia found that there were 5 domains for creating a dementia capable community:

- The physical environment
- Local facilities
- Support services
- Social networks
- Local groups

The five ways described how people connected to their local community are;

- Through local groups
- Through the use of local facilities
- Through walking in their neighbourhood Through the use of support services

Social action

The Coalition Government expresses social action as fostering and supporting a new culture of voluntarism, philanthropy and social action.

In our Think Piece we suggested that for dementia this means harnessing the power of social action to support and enable people with dementia to remain in their own homes, their own neighbourhoods and their social networks for as long as possible.

This would require the general public having a greater understanding of dementia and how they can support people to remain as active members of those neighbourhoods and communities.

The Think Tank heard a trigger presentation from Rosemary Hurtley, a parish councillor and community activist in Cranleigh Surrey. Rosemary outlined the inter-generational work taking place in her community that is based on positive citizenship. Kate Jones from Bournemouth and Poole Community Health presented the work they have undertaken with retailers in the Westbourne area of Poole.

We posed the following questions to Think Tank participants:

1. What can a community/neighbourhood do to support people living with dementia?
2. Who should lead community action?
3. What is the role of volunteering in improving the lives of people with dementia?
4. What can philanthropy contribute to the lives of people with dementia?

The following is a summary of the round table discussions.

The Think Tank concluded that the places where people live and engage socially are vital to a sense of well-being and belonging. Exclusion from communities and neighbourhood is all too frequently a consequence of dementia because a person often experiences reduced ability to follow the normal rules of social engagement and they can become lost or disorientated in physical spaces – this is due to marked cognitive impairments over time.

The Think Tank focused on the purpose of community and neighbourhood in a persons' life and about the desired outcomes of community action. Some of the outcomes included;

- Communities and neighbourhoods as places where people with dementia feel safe both physically and socially
- Places where other people understand what dementia is and how it affects a person so they are supported wherever they go

By 'community' the Think Tank included geographical communities (this report will sometimes use the term 'neighbourhood') as well as communities of interest.

The Think Tank acknowledged the importance of cultural sensitivity and lifestyle preferences as not everyone wants to be included in community activity and some cultures prefer to engage in family and extended family networks rather than wider community. In the same vein, some people do not want to work with the label of dementia whilst others are keen to speak openly about their dementia in order to raise awareness and to support other people with dementia. So, whilst acknowledging the nuances of a person's relationship to their community, there is still much that can be done to understand the boundaries of community and neighbourhood in this context.

The Think Tank believed there was much that communities can do to support people living with dementia and that people with dementia continue to have much to offer the community.

Permission to become socially active

It was acknowledged that some people feel the need to have permission to take social action in their community and neighbourhood. For example, some neighbourhoods do not mix socially. For many there remains a stigma around dementia and so it is often kept behind closed doors. For some people, the idea of crossing the threshold to let neighbourly support in or to offer neighbourly help is

difficult to negotiate – this may be informed by assumptions of others leading stigmatising behaviours that exclude

The Think Tank endorsed the notion that social action is a powerful catalyst for change within communities and can have a substantial impact on reform of services too.

People with dementia can play a vital role as agents of change in communities through awareness raising and volunteering but there are political issues to be addressed and these are explored in more detail on the community empowerment section of this report.

Mapping community facilities

Social action needs to be targeted to maximise its impact. One route to targeting was thought to be mapping the community facilities and social interactions of people with dementia so that it is known where people connect with their community. This links well to the work on community assets.

The mapping exercise is one that can be carried out in every community although there was support for the development of a dementia community mapping resource or toolkit. A few suggestions of how mapping could be done were offered by participants of the Think Tank;

- invite a number of people with dementia in a locality to map their use of community facilities to identify the most frequently used facilities. By joining up a number of personal maps it might be possible to link people locally who have similar interests and who can support each other in pursuing those interests.
- Place boxes in all community facilities and invite people with dementia to drop a token in the box each time they use the facility. Questions could then be asked about why some facilities are frequently used, and why others aren't. People living with dementia and those who are responsible for community facilities can then engage in a dialogue about what can happen to improve community facilities from the perspective of persons living with dementia. Providers of specialist dementia services might then have a role in supporting those improvements, to help services 'think dementia'

The Innovations in Dementia research showed that local shops are a key community touchpoint for people with dementia. The Think Tank heard from Bournemouth Community Health Trust and the local Alzheimer's Society who provide information and training about dementia to local retailers. The retailers can then pass on information to their customers about local memory services and other forms of support.

Raising awareness and understanding

Information about - and understanding of – dementia was thought to be a vital step in encouraging people with dementia to engage in social action and to encourage other people to act socially in respect of dementia.

Lack of knowledge and understanding as well as stigma are the route causes of exclusion from communities. The Government's dementia awareness raising campaign was thought to be a good start and there is much more to be done. Local engagement was thought to be necessary to normalise dementia and the Think Tank suggested a variety of ways in which this could be achieved;

- Use the Human Library⁴ project to raise awareness of dementia. The Human Library brings people together to reduce prejudice, break down barriers between people, increase social cohesion within communities by providing safe spaces.
- Intergenerational projects were thought by many participants to be key to raising awareness and understanding and simply bringing people together.
- Invite local people into services for people with dementia such as memory cafés and care homes to encourage greater understanding of dementia through learning from people with dementia.

Community readiness

The Think Tank understood that different communities are at different states of readiness to address issues of dementia.

The Think Piece circulated to participants prior to the event raised the notion of dementia capable communities. The Think Tank debated the relative merits of dementia specific community development with some concluding that community development should be seen in a wider context rather than through the narrow lens of dementia. This issue requires further exploration to ascertain if people with dementia really can benefit from general community development or whether dementia specific programmes would deliver better results. Evidence should be taken from existing community development projects.

Community empowerment

The Coalition Government defines community empowerment as ‘creating communities and neighbourhoods who are in charge of their own destiny, who feel if they club together they can shape the world around them.’

In our Think Piece we suggested that for people with dementia this translates as ensuring that people living with dementia remain active agents in their community and neighbourhoods, that their contributions are valued and respected. Where people with dementia who can no longer remain as active participants in their communities remain as respected and valued members of those communities and the communities have positive regard for people living with dementia.

Andrew Chidgey provided a presentation on Alzheimer’s Society’s Community Dementia Forums. Toby Williamson from the Mental Health Foundation outlined some of the key issues in approaching user-led organisations.

To explore the issue in more depth we asked Think Tank participants to think about the following;

1. What can be put in place to enable people living with dementia to feel empowered and in charge of their own lives?

⁴ <http://humanlibrary.org/> Martin Etheridge Human Library UK National Co-ordinator
03034441340

2. Who or what organisations are in a good position to make community empowerment a reality?
3. What difference will empowerment make to the lives of people living with dementia?

The following reflects the ideas that emerged from round table discussions.

The work presented by Innovations in Dementia showed that a number of the people with dementia who participated in their research lacked confidence and had low expectations of what could be available to them in their communities.

People with dementia said that as their dementia had progressed they were worried about their ability to cope and they were concerned that people didn't understand or know about dementia. Almost without exception – people blamed dementia, rather than shortcomings in the environment or community.

Whilst the Think Tank respected the right of people with dementia to create their own definition of empowerment it was also felt that the lack of confidence and low expectations limits the potential for people with dementia, as a community of interest, to become more empowered and to take more control of their own lives.

The issue of empowerment is closely related stigma and to the relationship with professionals in care and support services. The Think Tank concluded that there is a need for some relinquishing of power by some professionals at the same time that people with dementia need to take back some of the power that is removed from them through stigmatisation and discrimination.

Social movement

The Think Tank addressed the issue of political and social status of people with dementia. The voices of people with dementia are not clearly or frequently heard at local or national level.

The Think Tank explored the parallel with social rights movements such as physical disability, working age adult mental health and HIV and AIDS movements and acknowledged there were lessons to be learned. For example, physical disability is no longer accepted as a justification for exclusion either in terms of physical access to social engagement and so too the presence of dementia should not be a reason for people being excluded. Initially there was huge stigma regarding treatment of people with HIV and AIDS but the young, vocal activists made it clear that was not acceptable and they soon gained rights to high quality services – at whatever cost. The same entitlements should be available to people with dementia.

The Think Tank debated the challenges presented by the medical and social model of disability presents. Many debates polarise the two models but it was acknowledged that both models have their place; medical models are right in terms of clinical interventions but individual pathology should not be the dominant model. Likewise, the mental health and disability movement has largely excluded dementia from activities relating to social models. Non-the-less a number of participants believed that dementia should look for coalitions in the belief that strength would be gained by developing collective empowerment. The Think Tank also explored a third

model; the community model where people with dementia are held in positive regard by and supported through their social and geographic networks.

The Think Tank suggested that one of the solutions to community empowerment would be the creation of a national network of user-led organisations that will raise the visibility and turn up the volume of the voices of people with dementia so that society and professionals are compelled to respond. In Feb 2010 Claire Goodchild Team commissioned a Think Tank on user-led organisations for people with dementia and the report is attached as annex c.

The Think Tank made a comparison with Mumsnet; there is currently no media coverage of issues relating to parenthood that does not include a reference to the position that Mumsnet takes. The ambition is that a powerful social movement of people with dementia will emerge and will be a prominent, first call reference for all things relating to dementia.

Other methods of empowerment for the community of people who have dementia include;

- Arts based activities where a person is able to express themselves through creative media. There is also the opportunity for the wider public to view and experience arts based work produced by people with dementia.
- Life story work is enormously powerful for raising the profile of individuals with dementia, particularly those with more advanced dementia for whom verbal expression might not be their primary means of communication.
- People who do not have dementia can learn how to communicate with people who do have dementia

The Think Tank addressed the challenge of identity and dementia. Whilst 2.1% of people with dementia are under 65 years of age, dementia is primarily a condition associated with ageing and thus is a victim of ageism. At the same time, people with more advanced dementia - and those who live in care homes - are absent from debates and most mechanisms of engagement (we regretfully acknowledge that the perspectives of people living in care homes and with more advanced stages of dementia were not included this Think Tank).

Public service reform

The Coalition Government's Big Society defines public service reform as removing centralised bureaucracy, giving professionals more freedom and opening up public services to new providers.

The Think Piece suggested that for people with dementia, public service reform meant enabling services to engage more effectively with community members who are living with dementia. For organisations to work in partnership with each others and to deliver the types of services and support best tailored to their needs and aspirations of people living with dementia.

The presentation from Trevor Hopkins from Local Government Innovation and Development advocated taking an assets approach to communities rather than a needs/deficit approach that is dominant in the public sector.

The Think Tank participants were asked to consider the following questions;

1. What are the advantages or challenges to public service reform as described above?
2. What kind of public service reform needs to happen to improve things for people living with dementia?
3. Who is best placed to make public service reform happen?

The Think Tank was clear that the role of public services is to ensure fairness of provision to disadvantaged communities of interest and geography. The public sector was introduced for a clear purpose and that should not be forgotten in the Big Society debate.

Yet, the Think Tank agreed the time is right to review the role of the public sector and particularly the relational dynamics between public servants and professional groups in order to rebalance personal and collective agency for action. The outcome of the review should be to unify people living with dementia and professionals and should certainly not polarise them. It was felt that many providers of support and services to people with dementia across all sectors know what needs to be done but often don't know how to get there so more support in change management is required. The value of time out for thinking, reflection and innovative planning was recognised as an important part of the solution.

Turning first to professionals, the Think Tank was reminded that dementia was probably being discussed in parallel by different groups of professionals across the country. Some participants surmised that some of those professionals simply wouldn't understand the conversations that were taking place in the Think Tank. Some participants in the Think Tank felt that dementia is too 'professionalised' or, more specifically, too medicalised. Whilst specialism is necessary to further the quality of support and services to people living with dementia, specialism needs to work within a wide context of other services and support and in harmony with people's lives. A good starting point for professionals to reform is to have at least as many conversations with people living with dementia as one has with professional colleagues.

Some participants challenged the current priorities set by the DH National Dementia Strategy programme. The initial strategy represented the breadth of issues that need addressing to enable people to live well with dementia but some participants suggested that people with dementia would not necessarily place early diagnosis as a priority. Some felt that the current programme was professionally – more specifically clinically – driven. The Think Tank suggested that the DH could work across government to drive a more rounded dementia programme.

The solutions to the imbalance of power between people living with dementia, professionals and the public sector include;

- the development of user-led organisations as described in the community empowerment section above
- a review of the cultural values of the public sector that either enable or disenable the voices of people with dementia to be heard and acted upon
- commissioners and providers across all sectors to understand the skills, knowledge and experiences that maintain and enable people living with dementia to remain strong, resilient and energetic

- an understanding of the comparative costs and outcomes of community based activity and professional services so that opportunity costs can be evaluated and resource allocation re-balanced as necessary
- service providers understanding their role in relation to a whole context of the life of the person with dementia and take a more enabling and facilitative one rather than a dominant one
- review how risk is approached and take a person-centred approach to enabling and managing risk⁵

One way to proceed is to examine who does what best and to rethink the distribution of public funding to support the full spectrum of needs that people living with dementia have. The notion of the public sector as *investors* in communities and neighbourhoods was supported by the Think Tank.

From a strength or community assets based approach this must include investing resource into *things* that are outside of the existing deficit, needs based focus of the system – investing in resources that people use to build and maintain resilience, well being and cohesion. This calls for a systemic approach to investment in communities.

The Think Tank also considered the exclusion of people with dementia from mainstream services and suggested that one of the solutions was for leaders to recognise the rights of people with dementia to access their services and to show leadership in ensuring that happens. The Think Tank suggested 3 possible routes to this solution;

- Rigorous application of the Equalities Act 2010
- Leaders accepting the responsibility to learn about the needs of people with dementia
- Empower locally elected members to ask the right questions about how local services are meeting the needs and aspirations of people with dementia.

The public sector has existing mechanisms by which this can be achieved; aligning a Joint Strategic Assets Assessment (JSAA) to the local Joint Strategic Needs Assessment (JSNA) helps investors understand more readily the useful resources needed by communities that are about place, participation etc.

Conclusion and next steps

There are interdependencies between social action, community empowerment and reform of public services. Ideally there will be a symbiotic development of the three elements of the Big Society for people with dementia.

The Think Tank was successful in exploring challenges and raising a wide of possible solutions to the problems.

This report will be widely disseminated. We offer it to policy makers, social entrepreneurs, researchers, commissioners and providers of mainstream and specialist services across all sectors and to local communities to take forward the issues and ideas that emerged from the Think Tank.

⁵ See Nothing Ventured Nothing Gained: risk assessment for people with dementia http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_121492

If we were to repeat this Think Tank in a years time we would be delighted to see evidence of tangible improvement to the quality of the lives of people living with dementia.

Our thanks to all presenters and to all participants for their hard work throughout the day and for their subsequent contributions.

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with editorial input from Simon Rippon

Annex A

Think Tank Attendance list

Surname	First Name	Job Title / Company
Abley	Clare	Nurse Consultant Vulnerable Older Adults, Newcastle and North Tyneside Community Health
Ash	Christine	EDUCATE
Barradell-Smith	James	Corporate Development Manager, Alzheimer's Society
Butterworth	Olivia	DH lead for Big Society and Voluntary Sector Policy
Chidgey	Andrew	Head of Policy and Public Affairs, Alzheimer's Society
Chipchase	Helen	People & Policy Manager, BT
Dartington	Tim	Writer and social scientist
Davies	Ursula	Senior Project Manager, Design Council
Downs	Prof. Murna	Head, Bradford Dementia Group, University of Bradford
Dunlop	Peter	EDUCATE
Eley	Ruth	Department of Health, National Programme Lead (Delivery), Older People and Dementia
Etheridge	Martin	Head Of Partner Engagement - Big Society Programme Team, Department for Communities and Local Government.
Foot	Jane	Independent Policy Advisor, LGID
Fury	Peter	EDUCATE
Gage	Chris	Director, Ladder to the Moon
Goodchild	Claire	Department of Health, NDS Implementation
Hare	Philippa	Programme Manager (Policy and Research), Joseph Rowntree Foundation
Harrison	Elaine	EDUCATE
Hurst	Philip	National Development Manager, Age UK
Hurtley	Rosemary	Managing Director, Relationships Care Community (RCC) Ltd
Kaiser	Polly	Mental Health Development Unit, National Lead for Mental Health in Later Life
Keady	John	Professor of Mental Health Nursing and Older People, Manchester University
Lee	Norma	Deputy Director, Professional Practice, Bournemouth and Pool PCT
McGettrick	Grainne	Alzheimer's Society of Ireland
McShannon	Jennie	CE, Federation Irish Societies
Milton	Steve	Innovations in Dementia CIC
Morris	David	Director, Inclusion Institute (University of Lancashire & Kings fund)
O'Shea	Eamon	Irish Centre for Social Gerontology, School of Business and Economics
Rauf	Akhilak	Health & Social Care Projects Manager, Bradford Council
Rippon	Simon	Regional Dementia Strategic Lead, North West Joint Improvement Partnership
Roberts	Sue	EDUCATE
Roberts	Yvonne	Senior Associate, Young Foundation
Robertson	Guy	LGID (Ageing Society programme)
Sands	Alice	EDUCATE

Savitch	Nada	Innovations in Dementia CIC
Schneider	Kate	NHS SW and the SW Dementia Partnership
Sharp	Samantha	Alzheimer's Society, Senior Policy Officer
Sidwell	Becky	DH Project Manager, Social Care, Local Government and Care Partnerships Directorate
White	Claire	EDUCATE
Williamson	Toby	Head of Development & Later Life, Mental Health Foundation
Wright	Katherine	Communication Manager, Nuffield Bioethics

A think piece for the Dementia and the Big Society think tank**16 February 2011**

Big Society is a major policy theme for the Coalition Government. The detail of Big Society is emerging as are the critique's on the opportunities and challenges that reform of the roles and responsibilities of central and local government and the relationships between the state and society.

This paper begins the discourse on dementia and the Big Society. It begins to explore the triangulation of the 3 central themes of the Big Society and particularly focuses on dementia in the community.

Context:

There are over 750,000 people with dementia in the UK and this figure will rise to over a million by 2025. The current cost to the UK economy is over £20 billion per year including an £8.2 billion to the NHS and social care.

The Department of Health in England published *Living well with dementia: a National Dementia Strategy* in Feb 2009 (1). The Strategy primarily focuses on improving health and care services and has prioritised the provision of health and care services - early diagnosis and intervention, hospital care, care homes and reduction in prescribing anti-psychotic drugs – in the Strategy implementation programme. The DH Strategy has also included some wider issues such as raising public and professional awareness through a national media campaign.

Whilst the main thrust of activity has been focused on improving health and care services, the Coalition Government's Big Society provides a platform on which to consider wider issues of living with dementia. For reasons of demographics, cost and citizen rights it is timely for society, policy makers and service providers to think about enabling people to remain in their social networks for as long as possible.

There are 3 key themes of the Coalition Government's Big Society agenda:

- Social action - fostering and supporting a new culture of voluntarism, philanthropy and social action.
- Community empowerment - creating communities and neighbourhoods who are in charge of their own destiny, who feel if they club together they can shape the world around them.
- Public service reform - removing centralised bureaucracy, giving professionals more freedom and opening up public services to new providers.

In relation to dementia these three themes might translate to:

Social action: harnessing the power of social action to support and enable people with dementia to remain in their own homes and their own neighbourhoods and social networks for as long as possible. This would require the general public having a greater understanding of dementia and how they might support people to remain as active members of those neighbourhoods and communities. And how, through social action such as volunteering, people living with dementia can be best supported in social networks and in using community resources.

Community empowerment: ensuring that people living with dementia remain active agents in their community and neighbourhoods, that their contributions are valued and respected. Where people with dementia who can no longer remain as active participants in their communities

remain as respected and valued members of those communities and the communities have positive regard for people living with dementia.

To enable this to happen

Public service reform: enabling public services to engage more effectively with community members who are living with dementia For organisations to work in partnership with each other and with people living with dementia to deliver the types of services and support best tailored to their needs.

The motivation and incentives for organisations, neighbourhoods and individuals to engage with dementia are varied. For example;

- Individuals who have personal experience might be motivated by the desire to see improvements in the quality of life and respect of people with dementia and, where they have received good quality support, might want to 'give something back'
- Business sectors might see commercial advantages in providing good quality services to people with dementia or they might want to discharge their social compact by supporting projects related to dementia
- Neighbourhoods might recognise that they have people living with dementia amongst them and want to be more inclusive of all community members

Because different motivations manifest in different endeavours and result in different gains there is a need to develop a large framework for what the Big Society means for dementia. At the Think Tank we aim to begin creating that wide framework. We suggest that a assets perspective is a useful way of approaching the subject.

An assets based approach

An assets approach values the strengths, capacities, skills, knowledge and connections within individuals and communities and seeks to maximise these assets. Traditional approaches focus on deficits, problems and needs with responses from services to provide more and more provision to 'fix the problem'. This leads to dependence on outside support and a negative story of place and identity. An asset approach builds community solutions in a more sustainable way and more efficient use of outside resources. Such an approach also takes a systemic view of the person and place in terms of assets, solutions and resources.

Two thirds of people with dementia live in their own homes in the community. The remaining third live in long term care settings - also within neighbourhoods and communities. For those living in their own homes and for some of those living in care homes participation in normal community activity is vital for their well-being. It is therefore logical that assets are applied to communities to develop *dementia capable communities* to create places that are "friendly", "safe" and "enabling" for people with dementia. This approach has potentially great utility for the sectors of health, wellbeing and social care support; the paradigm has a strengths based view of people and place as opposed to a deficits or needs based view, has at its heart a focus on place based partnerships and power sharing across sectors, with people⁴. We are currently developing a dementia community assets models which planners and people living with dementia can better understand the component features for Dementia Capable Communities illustrated across 3 levels - dementia aware, friendly and capable^{*c}.

The National Dementia Strategy says of the needs of people with dementia that at particular touch points people living with dementia require the support of specialist services but acknowledges that for much of the time "some people will just want access to services that should be available to everyone locally, such as transport, leisure, housing and information" (p47). The challenge for the community – and service providers - is to understand how they can support a person's continued engagement as active participants and to support those who can no

longer actively engage and the challenge for specialist services is how they can support the community to be more knowledgeable and inclusive.

An assets approach aligns with the Big Society agenda in the following way;

- i) Developing social action: that illustrates an ethos of people forming and using networks, volunteers, community support circles that support people to live well with dementia and that impact on the issues of stigma and discrimination.
- ii) Building Community Empowerment: That mechanisms are set out wherein local people can readily engage with local service planners, providers to best shape and inform outcomes and benefits – a co produced agenda.
- iii) Public Service Reform: Through local engagement, people more readily shaping the type of services and community assets that need investment. This will see triangulation with commissioners/investor, providers and local people who may use such resources directly or have a vested interest in how resources are utilised.

As the momentum grows in these 3 areas; where people are increasingly living well with dementia, key strategic outcomes would be realised that illustrate greater individual and collective involvement in local communities, better processes for engagement and co production in place shaping and increased investment in social and community networks that build cohesion.

We acknowledge that such a shift will require a radically different mindset in some public and private sectors and a move toward investing differently which will be a challenge in the current financial climate.

We accept that the current economic climate for local systems is difficult but we would encourage a discussion and review as to how the points highlighted in this paper can be seen as part of a new system response to these difficulties.

References:

1. Department of Health 2009: Living Well with Dementia – a national strategy for England.
2. Building the Big Society: Cabinet Office May 2010.
3. The National Dementia Declaration: Dementia Action Alliance October 2010
4. A glass half full: How an asset approach can improve community health and wellbeing: IDeA (part of the LGA group) March 2010
5. Mental Capital and Wellbeing – Foresight Group - Scientific Review B3 2008.
6. Mental Capital and Wellbeing: Foresight Group 2009

Note

* a. McKnight J et al use this word to mean resources which are available to and used by people and seen as assets.

* b Living well with dementia – We use this term to account for the person with the diagnosis of a dementia and those people associated with that person, friends, family members etc often involved in the persons life and networks.

*c Dementia Capable Communities – A Framework for Action and Understanding. – Simon Rippon & Claire Goodchild at www.dementiacapablecommunities.org in 2011.

Authors: Claire Goodchild (DH) and Simon Rippon (DHNW), January 2011

Developing a model of engagement for people with dementia – report from Think Tank Feb 2010

1. Engagement with people with dementia – background

A one day ‘thinktank’ was held on 24th February 2010, in London. The purpose was to bring together key people to discuss what the Department of Health could do to support the development of a model of engagement for people with dementia. Innovations in Dementia, a community interest company that carries out user involvement work with people with dementia, were asked to organise and facilitate the day.

2. What is the purpose of engaging people with dementia in developing policy and services?

- To put people with dementia in control of their lives as individual citizens and to promote the wider involvement of all people with dementia in service development and delivery.
- To ensure that public resources are used most effectively aligned to meet the needs of people with dementia, their carers and families.
- To make sure that services recognise the specific and changing needs of people with dementia.
- To develop evidence about what is most effective in supporting people with dementia, their carers and families to live their lives with dementia.

2.1. **Programme:** Short trigger presentations were given to encourage people to think about the type of models that might have some relevance for ongoing engagement with people with dementia:

- *Edward McLaughlin* from the *Scottish Dementia Working group* talked about a user led campaigning model, run by and for people with dementia, with a paid person to support the group’s activities. The group has 85 members, with approximately 5 very active members who make public presentations. The group have influenced a range of organisations including the Scottish Mental Health Collaborative and the Scottish government.
- *Lynne Elwell* from Partners in Policy Making described the training courses they run to equip adults with disabilities and parents of children with disabilities to understand and navigate their way through the health and social care systems. To build capacity, graduates of the courses then train other individuals and families.
- *Tony Bennett* from *Carben Consultancy and Training* described the *Citizen Leaders* programme. Tony attended a Citizen Leader’s Academy to gain knowledge and skills to speak up as a carer about

self-directed support and individual budgets. There are currently about 20-30 active citizen leaders across the country

Presentations were followed by small table and large group discussions to explore what a good engagement model for people with dementia might look like, including how it would work and the support that would be needed. Suggestions were put forward for the design of possible models that would support the engagement of people with dementia in health and social care.

- 2.2. Participants:** All invited participants had an explicit interest and perspective on engagement work with people with dementia. 20 people participated in the day, including people with dementia and carers, and representatives from The Department of Health (national and regional leads), For Dementia, Alzheimer's Society, NHS Confederation, Dementia Advocacy Network, London Borough of Camden, Mental Health Foundation, Bradford Dementia Group, Innovations in Dementia CIC. Rachael Litherland from Innovations in Dementia facilitated the day.

3. General principles of a model of engagement

There was a lot of consensus at the meeting about the purpose and desired outcomes for what any engagement model should look like.

The conclusions were that any model of engagement should be:

- *User led* - driven by and centred on people with dementia
- *Flexible* - able to support the engagement of people with dementia in the things that are important to them but also to act as a collective voice of people with dementia
- *Representative* – of all people with dementia, including those with more advanced dementia. This needs to recognise the importance of carers and advocates, particularly for people in the later stages.
- *Willing to make the most of* existing resources and networks, rather than starting from scratch. This might include other engagement models, as well as families and advocates
- *Able to equip* people with the necessary skills and confidence to participate and engage – this includes people with dementia but also those that would support people to be engaged and involved