

Review of the Dementia Statements

Companion paper



League of Minds Dementia group who contributed to the review of the statements

I have Alzheimer's – it does not identify me and I, and all the members of the redrafting group will not be made ashamed of what is beyond our control.

This process has given us a voice and our voice needs to be heard.

- Shelagh Robinson, Consensus Event



THE DEMENTIA STATEMENTS

These statements were developed by people living with dementia and their carers.

The person with dementia is at the centre of these statements. They represent everyone living with any type of dementia regardless of age, stage or severity.

The “we” used in these statements encompasses people with dementia, their carers, their families, and everyone else affected by dementia.

These rights are enshrined in the Equality Act, Mental Capacity legislation, Health and care legislation and International Human Rights law.

- **We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.**
- **We have the right to continue with day to day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.**
- **We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.**
- **We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.**
- **We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.**

Notes and guidance to accompany these statements can be found at:

www.dementiaaction.org.uk/nationaldementiadeclaration

INTRODUCTION

This document aims to explain the process of the 2016/17 review of the Dementia Statements (previously known as the 'I' statements or National Dementia Declaration).

There will be additional documents that explain the legal basis for the statements, and which provide information on implementation.

BACKGROUND

In 2010, 41 national organisations (that went on to form the Dementia Action Alliance or DAA) asked people affected by dementia, and other key stakeholders, what type of care and support they would hope to receive in the future. Informed by these conversations, they created the National Dementia Declaration, a set of seven expectations or Statements of what life should be like for people with dementia. These Statements were used to inform the Prime Minister's Challenge on Dementia, which was published by the Department of Health in 2012.

Since the Declaration was published a huge amount of change has taken place in dementia policy in England. The 2009 strategy has been followed by two Challenges from the Prime Minister, which aim to transform the care and support people with dementia receive, as well as increase awareness and understanding of the condition across the country. The Prime Minister's Challenge 2020 Implementation Plan also contained a particular commitment to review, taking into account the progress made since the statements were originally published¹:

"contribute towards a review of the National Dementia Declaration, recognising the progress made since the "I" Statements were published in 2010."

Alzheimer's Society, as members of the DAA, offered to lead this review on behalf of the DAA.

GOVERNANCE

This project was informed by a reference group of people living with dementia and by a steering group of organisations who used the original National Dementia Declaration statements in their work. As the National Dementia Declaration statements were central to the work of the DAA, there was extensive overlap between membership of the steering group and membership of the DAA Steering Group. Separately, the DAA Steering Group were updated on the progress of the review and were able to provide input and feedback at Steering Group meetings.

The final statements were also reviewed by the Programme Board for the Prime Minister's Challenge Champion Group at the Department of Health and were endorsed by this group on 12th April 2017.

¹ The first stage of the Dementia 2020 Citizen's Engagement Programme began on 2nd November 2016 with the launch of a Department of Health survey and accompanying resources for people with dementia and their carers.

EVIDENCE GATHERING

Information was gathered for this project in several ways. These included:

Groups and interviews

- There were 15 groups that ran with people with dementia and carers about the statements between December 2016 and March 2017. These were organised through Alzheimer's Society and contacts within the NHS. To reach as many people as possible, one of these groups was specifically organised with the South Asian community, and two were with groups of people with young onset dementia. Additionally, people from Black, Asian and Minority Ethnic (BAME) communities and people with young onset dementia attended the other groups that ran. Due to the nature of these groups, they tended to be with people with dementia who were well supported, living in the community and in the early stages of the condition. Almost 80 people were consulted through these groups.
- As well as these groups, we ran 4 one-to-one interviews with people who wanted to contribute to the review. These were either on the telephone or face to face. 3 of these were with carers, 1 with a person with dementia.

A selection of quotations and case studies from these groups are available in appendix 1.

A survey of DAA organisations

An online survey was sent to organisations who were members of the Dementia Action Alliance to gather their views on the current statements including how they use them. 26 organisations responded to this survey. Selected results from this survey are available in appendix 2.

Literature review

We conducted a literature review to summarise the changes that had occurred since the original statements were published, and to provide some background and context to the review. Some of the themes covered in this review included research, carers, human rights and health and social care services. The literature review is available in appendix 3.

Information from Alzheimer's Society research – *Turning up the Volume: Unheard voices of people with dementia*

In 2016 Alzheimer's Society commissioned Ipsos Mori to do some research among people with dementia and carers. This culminated in the report, 'Turning up the Volume: Unheard voices of people with dementia'. The project team reviewing the statements was able to use some of the information gathered by Ipsos Mori to have insight into the views of people affected by dementia, who we did not reach through our other work. There were four parts to the research that we were able to use:

- In depth interviews with people with dementia that were mostly not in touch with Alzheimer’s Society and some of whom were in more advanced stages than the people we were able to reach through groups
- A survey of 500 carers reached through Ipsos Mori’s Omnibus survey
- A questionnaire that was completed by 147 people with dementia in touch with Alzheimer’s Society services in Manchester, Kent and Surrey. This was the pilot for a larger survey which was completed in 2017
- A poll of the general public.

Additional information on this project is available at:

www.alzheimers.org.uk/info/20093/reports/1100/turning_up_the_volume_unheard_voices_of_people_with_dementia/3

All of the evidence received was analysed and 6 key themes were identified. These were:

- Identity
- Independence/ interdependence/ dependence
- Community/ isolation
- Carers
- Research
- Care

More details on these themes are available in the ‘Research findings’ section of this document.



Dementia Voice Younger people’s group, who contributed to the review of the statements

DRAFTING EVENT

A drafting event took place on 20th March 2017. This was attended by nine people with dementia (three of whom were accompanied by their carers) and three former carers.

Each person attending the day had been assigned one or more of the key themes listed above and was given a summary of evidence on each theme to read beforehand. The session addressed each theme at a time, asking the people who had read the evidence on the theme to summarise the key points they had taken from the reading. There was then a discussion of the key points. At the end of this discussion, the group made an attempt to draft a statement on the theme. This was written up on flip chart paper and the wording discussed and amended by the group.

As each statement was drafted, it was then displayed around the room and individuals were invited to stick comments on them throughout the day. The draft statements were circulated following the day and some additional amendments were made.

At the event, each person was given an 'I want to speak' card to ensure everyone could contribute their ideas throughout the course of the day. Everyone was also given a packet of post-it notes so they could write ideas down throughout the day.

Throughout the day, the group decided that each statement should begin with the term 'we' rather than 'I' and that they should follow a rights-based approach to reflect the legal rights that people affected by dementia have.

CONSENSUS EVENT

A consensus event took place on 5th April 2017. This was attended by people with dementia (some of whom had attended the drafting event), along with representatives of key organisations who used the statements, including the DAA Steering Group. Minor changes were made at this event and the final statements were agreed upon. It was agreed that there should be supporting documentation to accompany the statements, detailing their legal basis and also guidance for implementation.



Consensus event

APPENDIX 1

GROUP RESEARCH FINDINGS

This section shows selected quotations and comments from the groups. These are arranged according to the themes which were identified.

IDENTITY

“I am still the same person that I was yesterday”

- One group talked about the importance of seeing the person and not just the dementia. They suggested there was an instant assumption you couldn't do things, and people reported various occasions where they had been helped across the street, even though they did not need this.
- “Some people I have told [about my dementia] and some people I haven't. The people I have told change like that [clicks fingers]...If they treat me differently, I say ‘you can stop doing that right now’”.
- One person with dementia commented “[What is important to me is] carrying on doing everything that I do for as long as possible”
- Another commented “I am still the same person that I was yesterday.”
- Another commented “It doesn't really affect my life or my lifestyle at all, apart from the driving... I am not arguing against having dementia. I am arguing against what they are telling me I can't do”.
- Another commented that what was important to them was “Being respected as a human being, not as a diagnosis”
- Another commented that what was important to them was 'respect, self-respect as well as respect of others'
- One group commented that the statements should be adapted to include “Rights and Human Rights”

It was important to people to maintain things which were important to their identity:

- Members of one group talked about their Christian faith. They said “God walked and talked with me, and still does – It's important to be in tune with what is right.” and “I was brought up with faith – it was a turning point in my life at childhood”
- One group commented that they still want to do what they want to do (from baking, to writing, to knitting), and don't mind being supported in that, as long as they can still do it themselves. Another group said that continuing to undertake hobbies and personal interests was important – the examples given were art, gardening, remote control vehicles, games and puzzles.
- Maintaining relationships were central in this. A person with dementia commented “I'm Grandpa – it's who I am – it's important – and they all respond to me in that way”

One thing which was important was a sense of purpose:

- Where people had had to give up things which gave them purpose, this was missed. One person with dementia commented that he would change “to be able to work again- a feeling that integration and social interaction are important”. Another said “To be able to volunteer in the community again”
- One person with dementia commented that what was important to her was “Having relevance and feeling part of life”
- At one group one of the people with dementia volunteered at her local Alzheimer’s Society “It does more for me than it does for them” She spoke about still feeling useful and still being able to make a contribution in life.
- One mentioned the importance of still being occasionally consulted by her old work – it gave her purpose and her opinion was still valued.
- One gentleman still does his job six mornings a week (cleans stables – friend is a donkey breeder, three are foaling at the moment) – he will be ‘buggered’ when he can’t do that anymore.
- People with dementia in some groups talked about the sense of purpose participating in research trials gave them: “Makes you feel they haven’t put you out to grass/forgotten you”, “Good to make yourself useful”

Dementia itself can be a challenge to identity

- Some participants questioned the changes in themselves they saw due to the dementia “‘Why do the memories from long ago stay but the short ones go?’ Somebody else in the group responded – “If you knew that you’d be a millionaire”
- One person commented that it was important to her that she kept a “video diary – allows me to recall day to day events”
- Another person with dementia said that what was important to her was “To be able to recognise family in the future”
- When asked what they would change, one person said “[I’d change my] memory – give it me back – losing memory means losing context which is what gives [me] fulfilment.”
- Others reported frustration and anger in themselves. One commented that she would understand a carer being frustrated with her as she is frustrated with herself.
- There were particular losses where people with dementia were losing ‘everyday’ skills – loss of reading (“I can’t follow it now”) and writing (“My writing used to be small but is now diabolical”) were mentioned more than once.
- A South Asian carer commented that he could see his mother getting frustrated because she knew what she wanted to say but she couldn’t find the language to say it. This was compounded as she lived in a country where her first language was not widely spoken, and she had lost any of the second language that she had had.

DEPENDENCE/ INDEPENDENCE/ INTERDEPENDENCE

Dementia affects a person's ability to be independent, but people are finding ways to manage this, usually with the help of a carer

- One person with dementia said 'I is for Independence' (implying that these [the previous 'I' statements] are all 'independence' statements)
- One group reported loss of independence as frustrating. One person with dementia reported how her son had taken over all of her finances ("He worked at the Bank of England, so I trust him".)
- Many people talked about driving, and how dementia has meant they had to give up driving.
 - Many talked about how their carer was their lifeline as they still drove for them.
 - One person with dementia combatted the sense of loss that accompanied not being able to drive any more this by going on lots of trips and holidays with his wife, so he was still able to have the sense of freedom.
 - Another talked about having to give up lorry driving.
 - One talked about how he took responsibility for himself in giving up driving. He had a bad accident and felt that he had to be responsible to the rest of the community and give up his licence
 - One talked about how he now followed the Sat Nav on his car during every journey, as he had started 'automatically' driving familiar routes rather than getting to where he wanted to go.
- One person with dementia talked about how he used technology to help him remain independent. He had linked his mobile phone to his wife's mobile phone so they could both know where each other were.
- One group told lots of stories where the level of risk which was acceptable to them was not acceptable for the carer/others around them. One person with dementia said about how his children had gone into his garage and taken away his power tools without consulting him.
- Pets were very important to one group. One gentleman has always had dogs – 'wouldn't be without the dogs' – they make you get up in the morning – great company – can talk to them and they don't answer back

Remaining as independent and engaged as possible was seen as important

- One person commented it was 'interdependence, rather than independence - because being independent means to be alone'
- Several carers from the South Asian group commented how the person with dementia they cared for would sleep all day unless prompted to do otherwise. These carers felt it was important that they were encouraged to be physically and mentally active and were deeply concerned there weren't services available which helped them to do this.

However, it was accepted by many that independence would not be possible forever and some were planning and taking steps for the future

- One person with dementia reported “I threatened my children that I would ride my bicycle the other day – In my mind I think I can still ride a bike like when I was young”
- A carer reported “I get very nervous. Very worried.” This was about the carers own health issues “If anything happened to me, what would happen to him?”. This couple were actually moving out of London to be closer to their son, in accommodation more suitable to them. They reported the enormous emotional upheaval of this as they had been in their home for 55 years. She said of the emotional battle “I am fighting this each day”

COMMUNITY/ ISOLATION

Many people talked about how they valued human connection:

- At one group interaction was important to everyone. Several people said that they consciously went out of the house every day to groups, cafes or to go shopping in order to “still feel part of society” and connected. At this group, it was felt that the services which were there were more about “socialising” than information or dementia support.
- Another group talked about the importance of friends and family in keeping them connected - it was difficult with having to stop driving and family living at a distance, but generally “they are very good”.
- One person with dementia commented “[What is important to me is] being part of a community – meeting other people”
- Another commented “Feeling you are part of other things” and involved in wider society was important.
- One group fed back “Both members of the group decided belonging and being valued were the most important words to them out of the choices. They both spoke about how they sometimes don’t feel accepted as part of their community. They feel they are often excluded because of their diagnosis.”
- Another group felt relationships were the most common theme, both with people and with God, where people get support and value from having these strong and caring relationships. Most discussion topics came back to the importance of these relationships.
- Isolation was feared. When asked what she would change, one person with dementia said “Loneliness and isolation”
- One person with dementia questioned the word “community”: “Who feels part of a community these days? It’s outdated. People are more insular now. When I was little we knew everybody in the street, but now you just know next door. People keep to themselves. Women have to go to work, so that coming together doesn’t happen anymore.”

CASE STUDY: Mrs S

Mrs S was living by herself with dementia. Her son lived nearby and he and his wife visit every day. As her dementia had begun to progress the family had moved her in with them, but they told me that she had to move out as “she could not manage the stairs”. They were also concerned with her being isolated as they were both out at work all day. The carer had health issues, particularly had had heart problems. He said “It really gets to you”.

They found she really struggled with her speech and became frustrated as she knows what she wants but can't express it. She has a carer 3 times a day but she needs more than this. They felt she needed stimulation and to see other people.

This included remaining part of the groups or continuing/taking up new activities, with “support in the background” to enable them to do this

- One man talked about how important it was to him to still be involved in his church community. “Support in the background is massively important”. This man talked about the parish nurse associated with his church, who had written about dementia in the parish magazine.
- One South Asian carer commented how her mother valued the older people's group at her local temple as there were lots of people there who she knew when she was working, who she could catch up with.
- One person commented 'my husband and I like being healthy – so [what is important to me is] going to the gym'
- One person with dementia at a young onset group commented she wanted “More things to keep fit. I would like to go swimming but I don't want to go on my own. I want someone to come with me. I find the changing rooms and that noisy, maybe if they out on a relaxed class, maybe aqua aerobics.”
- One group commented that the statements should be adapted to include “a wider range of things such as faith, music, hobbies” The same group said that they should include “Transport”
- Someone from a group with younger people with dementia commented “If I am in the bank I will explain that I have early onset Alzheimer's. They have changed the ATMS recently and they have made it too complicated. You have to go to different ATMs for different accounts and statements. I didn't bother in the end. I need to speak to someone. People are more helpful if you tell them what you've got.”

Dementia was seen as an invisible illness

- One person with dementia commented the “stick says I have a bad leg, but no one wants to walk around with a sticker saying I have dementia.”
- One younger person with dementia said “They don't always believe me, they say you don't look like you've got it and I say ' what should I look like then?’”

Stigma from the community still exists, but societal attitudes were thought to be improving

- One person with dementia told the story of her husband's friend essentially turning around and walking away when he was told of her diagnosis.
- Another said that she had lost her best friend because of her diagnosis.
- One commented "Society's view on dementia needs to be more understanding"
- However it was felt that there was "more acceptance these days" and more help. There was more signposting. "You know where you are".
- The South Asian group felt dementia is still a taboo subject. The derogatory word in the native languages is still used, but it was felt that there had been changes in recent times. Some carers worried about the behaviour of the person with dementia in public places - if the person was shouting then they would be embarrassed if someone looked at them. Other group members encouraged this person not to feel embarrassed. It was thought that societal awareness increasing further would be good. One carer identified that people with dementia don't look like they have dementia, so the 'hidden nature' made stigma more difficult to tackle-if someone is shouting you don't know it is dementia. It was thought that the younger generation particularly find this harder as they don't have personal experience of dementia.
- Another group felt that things have improved and developed over time. Many of the people with dementia also cared for their parents and reported late diagnosis, poor quality care, for their parents, where a "put them in there and forget them" attitude prevailed in institutional care. They agreed that it was better than it was, with "more people who want to do something" and people knowing it isn't "something you can catch".

CARE

People still had a very variable experience of care

- For example, one person had check-ups with GP for diabetes but not dementia – GP does not really understand it

People felt that the system could be fragmented

- Two younger people in one group with dementia asked for a 'one stop shop' where people could get support with everything - not just their dementia, but benefits, housing etc. They had discussed the idea for this at a previous meeting
- One carer from the South Asian Community commented how the GP sent them to the memory clinic who just referred them back to the GP - "sent from pillar to post".

People desired continuity in delivery and for the same service to be available over a long period of time

- One carer, whose husband's dementia was advancing, discussed how support was difficult to access in her area. She wanted consistency in her support person, and a pro-active approach ("someone to ring every fortnight to ask how we are getting on") but this was difficult to come by.
- One of the groups for younger people with dementia asked for the same thing "More continuity (from services). Not having to ask for help. People say give me a call, but I forget. I forget who could help me or what they do. It would be nice if they rang every couple of months and just asked if everything is ok."
- In the group for the South Asian Community there had been a greatly valued course of Cognitive Stimulation Therapy, run in the languages the people with dementia had spoken when they are young and connecting them to their lives in the villages they grew up in. It ended after 12 weeks and the service have found it difficult to recruit bilingual staff to run the service on a continuing basis.

Others commented that they didn't know what they were meant to get, and could see a 'postcode lottery'

- One group were concerned that they saw divisions across individuals in their group who were in different local authority areas – the people in the 'county' local authority seemed to get more than the people in the 'city' local authority
- One group was housed in a specialist dementia hub, and they were all appreciative of the services they were able to access there. They valued the peer support they got there and felt there was no stigma around dementia at the centre. There were added benefits that carers could socialise at the centre. However, they were concerned that people in other parts of the country were not able to access services which were as good – particularly people in rural areas. They mentioned issues of access along artificial boundaries - "Literally a postcode lottery" where one man had to argue based on his postcode that he should be entitled to attend.
- The South Asian group were entitled to access services across the NHS trust. However, community transport would not go across local authority boundaries. It was therefore very difficult to attend services nearby but in a different borough, despite these being tailored to their needs (being culturally sensitive, in their native language)

People with younger onset dementia and their carers asked for age appropriate services

- People with early onset dementia from one group had found it very difficult to access appropriate financial information related to working age benefits.

People asked for services which recognise the individual wants and needs of the person, their community and their interests

- A carer wondered if there was something tailored to her husband with dementia's particular interests, whether they would still be participating. She recounted how at a particular group he had been asked to decorate cupcakes, something which he would have considered demeaning.
- A South Asian carer commented that there needed to be provision which meets the needs of each individual. Her mother attends a day centre where she is the only Asian person. The carer is aware of day centres where this is different but there is not space there. She attends the older people's service run in her Sikh temple, but this is not dementia specific.

Services appropriate to the stage of dementia

- Diagnosis was seen as a key point across many of the groups. One person commented "Early diagnosis [is] a priority- [should come] from psychologists"
- In one group, there were mixed experiences of how a diagnosis was reached - some had a proactive GP, but others had to repeatedly raise their concerns, had found out 'by accident' because of other investigations, or had been repeatedly misdiagnosed.
- A person with dementia at a different group talked about how diagnosis had "opened the door" to support for him, but his carer confirmed how he had to return to the GP repeatedly in order to be referred for diagnosis. He said diagnosis was "like getting on board a ship - once you're on it goes smoothly".
- A carer who was interviewed discussed about how as her husband's dementia advanced and he was less able to 'help' in groups, they had become less useful to him as he didn't have a 'purpose' in going there. One person commented that they felt that the statement which addressed end of life care in the current version was 'unrealistic' - no-one could ever say with confidence that they would die free from pain.

CARERS

Carers were frequently mentioned as important in the group discussions. Support from family was seen as the main source of support, rather than from services:

- "I couldn't manage without my wife"
- "My support is my wife"
- One group talked about the importance of friends and family in keeping them connected - it was difficult with having to stop driving and family living at a distance, but generally "they are very good."

There was also concern about what would happen if something happened to the carer:

- One of the people with dementia reported being in floods of tears for 12 hours when his carer was in hospital - “When she feels secure, I feel secure”
- A carer reported “I get very nervous, very worried.” This was about the carers own health issues - “if anything happened to me, what would happen to him [the person with dementia]?”
- One person with dementia commented “My wife had pneumonia so we are carers for each other”

The role of family and carers could also sometimes be challenging for the person:

- One group said they feel guilty for calling on their children for help and don’t like to ask.
- Family often take control after a diagnosis and this can be hard for the person, especially if they are very independent. In one group, one person’s wife had taken over all the finances and he found it hard to let go - support from family has been great but every now and then the person gets resentful even though they are doing it out of love.
- Some objections also to the word carer being used all the time, as it is often their partner, family, etc.

Many people saw the absence of carers in the current version of the 7 main statements as a problem. When asked what was missing from the statements, many people mentioned carers:

- “Someone to voice my views”
- “Support from friends and partners”
- They pointed out that there was no direct statement about carers. One said: “She is the one that suffers the most from my condition.”
- They asked if there had been thought into support for different carer pairings (e.g. husband/wife, parent/child). One person with dementia who was also a carer herself pointed out that caring needed to be responsive to the personality and likes and dislikes of the person - “Go with the flow. Fit yourself into their lifestyle and not the other way around”
- There is not enough information given for carers, too little input - “my partner has lots of questions and no answers given”
- One group’s main criticism of the ‘I’ statements as they are is that they do not reference carers. Another highlighted that “Carers are not referenced at all - only in sub-statements”

Carers themselves felt that the need for proper support was really important:

- Key thing for carers is support – this can mean lots of different things
 - Includes education on dementia including information and advice but could also include peer support
- Entering a world of unknown when engaging with health services – carers need information to gain confidence in order to engage with services and challenge decisions if necessary
- Important to get carer themselves to recognise that they are just as important if not more important than the doctor – experts by experience

- Important for carer to be involved in decisions but they must have the confidence to do this
- Important phrase amongst carers is 'if only I knew then what I know now.'
- The Group run with the South Asian community highlighted the importance of supporting carers – for this group while families are keen to support their loved ones, it should not be automatically assumed that they will 'look after their own' and appropriate support services, tailored to their needs, should be available.
- A South Asian carer commented that her mother had only recently been diagnosed. She was only just learning where to go with support - "It is very hard to know what to do...we are just at a loss about what to do". This is alongside juggling other family commitments. She commented that she had struggled to get them both out and ready that morning. Even though the group wasn't until 11 it had taken her all morning to get them both together, just to go home in an hour.
- There needs to be education for carers "we haven't been taught - we just use our common sense". Structured education, like the Alzheimer's Society CRISP programme, was mentioned as helpful.

CASE STUDY: Mrs M

Mrs M commented that the most important thing to her was having time for herself. She is caring for her husband 24/7 and has difficulty doing this. He has advanced dementia and she has to manage issues around his continence. She and her husband are both in their late 70s. Her 3 children all live at a distance, and have jobs and small children of their own, so she cannot rely on them for practical support.

She has support from Social Care (4 visits a day) and 8 hours of sitting services in the week. She uses this time to go shopping as local shops are closing, it is difficult for her to get to the supermarket as there is very poor transport - she can only access community transport if her husband is with her, so she is reliant on bus services, and she is not very mobile herself. She cannot leave her husband alone as he falls frequently and is incontinent. She would like more sitting time in order to actually have some time to herself.

There was a particular issue with respite. She was assessed as needing a week of respite 6 times a year, but this has only been provided once. When she was sick and care was needed for him, her children paid for his respite, but this cost them £950 for one week. She now needs another operation but has been told that there is no respite available until the next financial year. She felt it was ridiculous that she had been assessed as needing something, but that it was not being delivered.

Carers felt their role in knowing the person was fundamental:

- Know person with dementia is at the centre of everything – *"as far as I was concerned, he was the centre"*
- When spoken to carers, all feel the same – all love the person and all want what's best for them
- Most important with carers is that they are involved in decisions as they know the person best

RESEARCH

Some people in the groups saw research as the most important word. This was frequently tied to hope for future generations, rather than research helping the person themselves:

- Hoping research will have better outcomes for future generations
- “The future to be more positive towards dementia” [in response to a question about what would you change]
- One person commented that when they were a child, if heard the word ‘cancer’ it was a death sentence but now, because of research it’s not - “I know it won’t benefit me but it might benefit my grandchildren’s grandchildren.”
- Some felt that more understanding (through research) can also help to address stigma.
- They asked for more research into the question of hereditary - many of the people with dementia had parents with dementia and they suspected that it did go down family lines - “When you have children, you just think “Oh my god!”
- At the South Asian group, one carer felt that research was very important. There needed to be more medical knowledge on what dementia is, how it is caused and what the best treatments and activities were for it. The family were giving the person with dementia vitamin and fish oil supplements as they believed this would help.

Some people felt like taking part in research gave them a purpose and a way to be helpful:

- One said “It makes you feel they haven’t put you out to grass/forgotten you”
- Another said “It’s good to make yourself useful”

Some also talked about the possibility that research could discover things to stop dementia getting worse:

- There was a discussion about things that might be helpful to stop dementia progressing. Mental activities (word searches) and remaining socially connected were felt to be really important. One person also felt that attitude and mind-set was important - “I’m not going to let this damn well beat me.”
- They wanted to know if there is anything you can do to stop it getting worse – had heard best thing to do is physical exercise (members discussed martial arts, tai chi and dog walking). Member said she stretches in chair because can’t do anything else – not allowed to drive, not allowed to walk on her own. Likes coming to groups because it’s hard to know what to do when sitting alone if there’s nothing good on TV.

A few mentioned the possibility that research could find a cure:

- Research – “next year I might be cured.” They suggested that it was important at the moment to them to know that it was going on, but that they doubted that as dementia progressed whether they would feel the same.

- When asked what they would change, some said “no dementia” which was often interpreted to mean the importance of finding a cure.
 - Some responded to this question specifically with “finding a cure”

They also talked about wanting to be involved in research and knowing more about what was going on:

- Yes, we are part of it [research]
- Some people in the groups were already taking part in clinical trials.
- Some people felt there was increasingly more interest in research but this was often concentrated in the South.
- Some said they don’t really know what’s going on in research – they know it’s happening but don’t know exactly what and would like to.
- Some thought that there was research going on but “as we are getting on we may not be able to take advantage of that.”
- One person commented that it was very important to know about research but can be depressing and hard to take part – you can see progression (in MRIs and CAT scans). Sometimes told that you are too far gone to be involved. Found out had no feeling in one finger through being involved in a research study. Also found out had lost 6% of brain.
- One gentleman has been asked to take part in trials and has said yes but can’t always do what is required (e.g. 90 minute MRI but he has a bad back)
- Another gentleman would like to be asked to take part in research

People also acknowledged the importance of responsible reporting when research happens:

- One group said that the press had to be responsible when they were reporting developments in reporting. One of their previous members had followed press reporting of research closely, and in one case had believed that coconut oil would slow down or halt his dementia. He had therefore spent large amounts of money on coconut oil, eating it regularly and bathing in it.

EVIDENCE GATHERING TONE, LANGUAGE AND STRUCTURE

We also received feedback from people with dementia on the tone, language and structure of the current statements as well as suggestions for improvement.

This was only through the groups and interviews which were specifically about the statements, and from the organisational questionnaire.

People acknowledged the challenge of getting something that applied to everyone:

- “These things are very personal – some people are sensitive and get offended, some are tough and take life as it comes – you can’t have too many rules [on the statements] as everyone is different.”

- [The group] recognised importance of all these things, but that perhaps their importance varied along their dementia journey - for example, knowledge and knowhow was definitely one of the most important things at the beginning; also “so much money is spent on creating supportive environment, but for example personal support does not happen so easily - it is easy to give people product, but it often isn't enough”

Many people felt the statements were too aspirational and didn't relate to their own experience:

- They were glad the statements were being thought about – “they're just not true.”
 - “These are all lovely in an ideal world, but...”
- The statements were described as “high fluted, poor language, unrealistic.”
- They also challenged the format of the statements – they did not like them all starting with ‘I’ and felt that they were not things they would ever say:
 - “[I would] never ever use those words.”
- One group felt these statements did not reflect the lived experience of people who have dementia.
- One group felt the statements generally reflect their hopes and aspirations. However, the group felt these statements were aspirational, rather than what was happening in reality.
- They felt like they wanted more about what it felt like to have dementia, particularly the feelings and thoughts of the individual.

Some people suggested that the statements should be written as aims, rather than statements.

People were receptive to the idea of changing the phrasing to a more rights- based approach:

- There was a lot of discussion around how they are phrased – some people thought they should be written as aims e.g. ‘I would like to have’ rather than ‘I have’
- It was felt the grammar needed changing as none of the statements are presently active. Instead of ‘I’ statements, they should be ‘I would like to have’, ‘we would like’, ‘I have a right to’ and ‘I need’.
- One group agreed they should change to; ‘I have a right to...’ Another fed back “It is good to have something to aim for but the wording is wrong. ‘I have a right to...’ is better”
- One group said that need to “be positive”

Some had comments on specific words and terminology:

- ‘I have received an accurate (rather than early) diagnosis’ more important, but emphasize a person-centred approach at times of uncertainty - meaning, some people may want to know even if there is a possibility, others may not until the diagnosis is certain, also considering their roles, financial support in place, etc. no one rule fits all.

- One person with dementia looked at the word “burden” - “I try not to be a burden.” This led to a discussion of some of the emotional symptoms of dementia – anger is a “blow up” and inevitable.
- One person commented “What is civil life? It sounds like holding an office in the council.”

There was also some discussion around how to refer to carers, or how to reach people who don't feel they have someone they would describe as a 'carer':

- My carer can access respite care if and when they want it... - there is not enough information given for carers:
 - “My partner has lots of questions and no answers given”
- Generally, people did not refer to their 'carer' - they referred to the relationship of the family member (“my wife”, “my son”). Occasionally they would qualify this (e.g. “Well, she's my carer now really”)

People also felt the statements were too long and some were repetitive:

- “There is a bit of overlap between some, and repetitions - these could be condensed, and others on the other hand may perhaps need breaking down into smaller sections - for example in I feel safe and supported in my home and community is too narrow/general.”
- Described as “very wordy” and “too long winded.”
- (Initial reaction to seeing all of the statements) – “That is ridiculous! There too many.”
- Some people just said “simplify them.”

EVIDENCE GATHERING APPENDIX 2: FINDINGS FROM THE ORGANISATIONAL SURVEY

SURVEY OF ORGANISATIONS

The DAA conducted a survey of its members to find out how they use the statements.

- 76% of organisations that responded used the ‘I’ statements in their work – this was predominantly as a way of understanding things from the perspective of people with dementia (86% of organisations used them this way).
- The organisations found the statements useful for various reasons:
 - “They reflect an ethos of care that we strive to deliver.”
 - “They are most useful in supporting care staff to identify people’s needs and provide care individual to them. They also encourage a sense of belonging and enhance well-being.”
 - “They challenge the idea that people with dementia should be isolated.”

Some organisations gave suggestions of why certain statements were less useful than others:

- Research – “purely because the other statements have a more tangible presence in people’s lives and challenges to these are encountered more frequently.”
- ‘Support’ can be ambiguous.
- There is some duplication
- “Nobody can simply and easily find evidence.”
- “They are still useful but have slightly less emphasis for the individual”

General feedback on the statements included:

- “Our main concern is that the ‘I’ statements are referred only focussing on the seven overall statements and insufficient time and exposure is given to the overall National Dementia Declaration. If we are going to focus on the seven overarching statements, we need to ensure that the needs of carers are more explicitly stated, recognised and respected.”
- “It is vital that the ‘I’ statements reflect the person’s wishes regarding how they want to live their lives and retain a sense of being actively involved in their community – whatever this community is. However, in order to enable this to happen, a greater degree of knowledge and understanding is required about the person and what matters to them as individuals in the context of their significant relationships with others. We need much more intense and bespoke work to be undertaken in BAME and LGBT communities to ensure that what support is provided is culturally competent.”

APPENDIX 3: LITERATURE REVIEW

The original 'I' statements:

I have personal choice and control or influence over decisions about me.

I know that services are designed around me and my needs.

I have support that helps me live my life.

I have the knowledge and know-how to get what I need.

I live in an enabling and supportive environment where I feel valued and understood.

I have a sense of belonging and of being a valued part of family, community and civic life.

I know there is research going on which delivers a better life for me now and hope for the future.

More detail and the sub-statements can be found here:

www.dementiaaction.org.uk/nationaldementiadeclaration

POLICY BACKGROUND: WHAT HAS HAPPENED IN DEMENTIA POLICY SINCE THE NATIONAL DEMENTIA DECLARATION WAS PUBLISHED IN 2010?

The change in dementia policy since 2010 has fallen within four key themes:

1. **Government policy on dementia**
2. **Relevant legislation**
3. **Broader health and social care policy and reform**
4. **The influence of rights**

The changes – particularly a shift towards a more personalised, rights-based approach to caring for people with disabilities including dementia – all have an impact on the way the National Dementia Declaration is formulated, used and understood.

1. GOVERNMENT POLICY ON DEMENTIA

The National Dementia Declaration was formed following the publication of the first national dementia strategy by the Department of Health in 2009. The strategy set out the government's plan

to transform the quality of life for people affected by dementia and covered three key areas: raising awareness and understanding, early diagnosis and support and living well with dementia.

Prime Minister's Challenge on Dementia 2012²

In 2012, Prime Minister David Cameron set a challenge to deliver major improvements in dementia care and research by 2015. This focussed on three key areas which would be coordinated by 'Champion groups':

1. Driving improvements in health and care
2. Creating dementia friendly communities and
3. Improving dementia research

The challenge built on the achievements of the previous strategy and accompanied the first annual report from the Alzheimer's Society, which explored how well people with dementia were living.³

Key actions from the 2012 Challenge included:

Driving improvements in health and care

One of the key commitments in this area was improving **diagnosis** rates and also improving post-diagnostic support. In November 2015, a 66% diagnosis rate target was achieved.⁴

Dementia friendly communities

Fostering **dementia friendly communities** aimed to address the lack of understanding and stigma that surrounded dementia. This would help to enable people with dementia to live and be supported in the community for as long as possible. The 2012 challenge set a target of 20 dementia friendly communities by 2015 and also wanted to engage national businesses and organisations in becoming dementia-friendly. A major public awareness campaign was launched in May 2014, aiming to get 1 million **dementia friends** by March 2015. Currently, there are over 1.7 million dementia friends and a new target has been set of 4 million by 2020.

Research

The 2012 challenge contained commitments to improving dementia research. As well as increase funding, Alzheimer's Society, Alzheimer's Research UK and the National Institute for Health Research (NIHR) launched '**Join Dementia Research**', which supports people to get involved in dementia research by matching them to appropriate studies.

Prime Minister's Challenge on Dementia 2020⁵

² Prime Minister's challenge on dementia: Delivering major improvements in dementia care and research by 2015 (Department of Health, 26 March 2012)

³ Dementia 2012: A national challenge (Alzheimer's Society, 2012)

⁴ NHS England, Mental Health – Dementia <https://www.england.nhs.uk/mentalhealth/dementia/>

The Prime Minister's Challenge on Dementia 2020 draws on the earlier challenge of 2012 and provides a series of aspirations to work towards and achieve by 2020.

The two key goals are to make England:

- The best country in the world for dementia care and support and for people with dementia, their carers and families to live and
- The best place in the world to undertake research into dementia and other neurodegenerative diseases.

The Challenge document was followed in February 2016 by an Implementation Plan⁶, setting out actions the Government and other bodies would take to achieve the aspirations set out in the Challenge. These fell into four main themes:

1. Risk reduction
2. Health and care delivery (including workforce training and development)
3. Dementia awareness and social action
4. Research

Risk reduction

By 2013, there was an increasing amount of evidence suggesting that leading a healthy lifestyle reduced a person's risk of developing dementia. Good diet, regular physical exercise, proper management of type 2 diabetes and hypertension, as well as avoiding smoking and excessive alcohol consumption could all reduce someone's risk of developing dementia (Barnes and Yaffe, 2011, Mangialasche et al, 2012). A healthy lifestyle from midlife onwards is likely to be particularly effective at combating dementia (Barnes and Yaffe, 2011). The development of this evidence culminated in the **Blackfriars Consensus Statement**,⁷ published in 2014 and signed by 59 organisations and individuals who were experts in dementia care and research. This Statement highlighted the need for a new focus on dementia risk reduction, given the development of a body of evidence demonstrating that it was possible to reduce the risk of dementia. Since that time, Public Health England has identified dementia as one of their priority areas. It is currently piloting incorporating dementia into the NHS health checks system for 40-64 year olds and has also launched the One You campaign, to promote healthy lifestyles amongst this age group.⁸

Health and care delivery

⁵ Prime Minister's challenge on dementia 2020 (Department of Health, Cabinet Office and Prime Minister's Office, 21st February 2015)

⁶ Challenge on dementia 2020: Implementation plan (Department of Health, 6th March 2016)

⁷ Blackfriars Consensus on promoting brain health: Reducing risks for dementia in the population (Public Health England and UK Health Forum, 20th May 2014)

⁸ Health matters: midlife approaches to reduce dementia risk (Public Health England, 22nd March 2016)
<https://www.gov.uk/government/publications/health-matters-midlife-approaches-to-reduce-dementia-risk/health-matters-midlife-approaches-to-reduce-dementia-risk>

The Government continues to focus on support both for people with dementia and their carers. Great progress has been made in improving diagnosis rates and the focus is now on post-diagnostic support. The Implementation Plan acknowledges that everyone with dementia is entitled to a social care assessment and if eligible, a **personal budget** (more detail can be found in the Care Act 2014). The plan also encourages better integration of health and social care through the Better Care Fund, launched in 2013.

There has also been a greater focus on improving the mental health of older people and this has been encouraged by the work of the Mental Health Taskforce, who produced a Five Year Forward View for Mental Health in February 2016.⁹ This recommended that NHS England should ensure that people who are supported in specialist older-age acute physical health services have access to mental health liaison teams as part of their package of care and that by 2020/21, no acute hospital should be without all-age mental health liaison services in emergency departments and in-patient wards.

There is also emphasis on housing and assistive technology to support people with dementia to live well in the community, including dementia-friendly design initiatives, training for the housing sector and social housing.

Raising awareness and social action

This focuses on developing and building the dementia friends and dementia friendly communities programmes both in England and internationally.

Research

The key action resulting from the 2020 Challenge is the establishment of a **Dementia Research Institute (DRI)** as well as commitments to increase funding. The Government is also committed to international research collaborations.

2, RELEVANT LEGISLATION

House of Lords Post-legislative scrutiny of the Mental Capacity Act 2005¹⁰

The **Mental Capacity Act (MCA)** is one of the most important pieces of legislation for people with dementia. In 2014, a review by the House of Lords showed that while the Act is well-intentioned and based on important principles it has suffered from poor implementation:

“The Act signified a step change in the legal rights afforded to those who may lack capacity, with the potential to transform the lives of many. That was the aspiration, and we endorse it... Our findings

⁹ Five Year Forward View for Mental Health (Mental Health Taskforce, February 2016)

¹⁰ Mental Capacity Act 2005: post-legislative scrutiny, House of Lords Select Committee on the Mental Capacity Act 2005 (House of Lords, February 2014)

suggest that the Act, in the main, continues to be held in high regard. However, its implementation has not met the expectations that it rightly raised.”

A key concern highlighted was the lack of awareness of the Act and its principles amongst the public and healthcare professionals in part caused by a culture within healthcare that is still based on paternalism and risk aversion. The inquiry found that capacity was not routinely assumed, supported decision-making was not routinely utilised and best interests decisions were unduly paternalistic, giving insufficient weight to the wishes and feelings of the person concerned. This lack of awareness also extended to the legal tools the MCA provides for people to plan ahead for a time when they might lack capacity to make a decision about their health by making an advance decision to refuse treatment or lasting power of attorney and welfare. These issues are especially pertinent for people with dementia because capacity can become affected as the condition progresses. The House of Lords were also highly critical of the Deprivation of Liberty Safeguards (DoLS), which they described as ‘not fit for purpose.’

The Government responded to this report with *Valuing Every Voice, Respecting Every Right*,¹¹ which aimed to address the recommendations put forward by the House of Lords. This included actions to raise awareness of the Act, embed its principles within healthcare and improve monitoring and implementation. Shortly after this response, the Government ordered the Law Commission to review the DoLS.

One year after the Government published their response to the House of Lords review, they produced a document evaluating what had happened in the one year since. The document acknowledged how integral the MCA is to various other Government policies:

“The MCA is not the only tool we have to drive this change. It is the shared aim of much of the Government’s activity; from our work on dementia and learning disability, to our work boosting the use of Lasting Powers of Attorney.”¹²

In this document they also summarised key actions taken:

- The Office of the Public Guardian has developed new, simplified Lasting Power of Attorney forms
- The Social Care Institute for Excellence (SCIE) created an ‘MCA directory’ of resources and information about the MCA
- A wallet sized card was developed by the Department of Health summarising the key principles and rights people have under the MCA
- The Local Government Association (LGA) and Association of Directors of Adult Social Services (ADASS) have developed an ‘Improvement Tool’ for local authorities to monitor their progress in implementing the MCA
- Health Education England (HEE), in partnership with the Academy of Medical Royal Colleges, have ensured the MCA is now part of the Foundation Programme Curriculum for doctors

¹¹ Valuing Every Voice, Respecting Every Right: Making the case for the Mental Capacity Act (June 2014)

¹² ‘Valuing Every Voice, Respecting Every Right: One Year On’ (Department of Health, August 2015)

- The Care Quality Commission (CQC) have embedded the MCA in the way they conduct their inspections

They also announced a new National Mental Capacity Forum, which would support and monitor implementation and spread good practice.

Deprivation of Liberty Safeguards (DoLS)

The **Deprivation of Liberty Safeguards (DoLS)** were introduced following a decision of the European Court of Human Rights which showed that there was no legal process in place for depriving people of their liberty when they lacked capacity to make a decision about the circumstances which would amount to a deprivation.¹³ This was in contrast to the legal framework in place for depriving people with a mental health condition of their liberty (Mental Health Act). The DoLS were developed to provide a legal process for depriving someone of their liberty including providing a procedure for someone to challenge a deprivation. Unfortunately, the DoLS have created a great deal of controversy and were described by the House of Lords as ‘not fit for purpose’ and are currently being reviewed by the Law Commission, which is expected to publish their report in March 2017.¹⁴ This controversy has been heightened since the *Cheshire West* case which reached the Supreme Court in 2014, at the same time as the House of Lords were carrying out their review of the MCA.¹⁵ This case redefined what would constitute a ‘deprivation of liberty’ by creating the ‘acid test,’ which was that a person who is “*subject to continuous supervision and control and who is not free to leave*”, is being deprived of their liberty. One consequence of this judgement was that a huge number of people are now considered to be deprived of their liberty, including people who live in care homes and supported living arrangements. Many stakeholders were subsequently affected by the DoLS procedures including local authorities, care providers and social landlords.

The impact of DoLS on people with dementia is huge – the majority of people in care homes have dementia (70%)¹⁶ and many will lack capacity to consent to their living arrangements and therefore require a DoLS authorisation. In the most recent figures, 51% of people with DoLS applications had dementia recorded as their primary disability.¹⁷ Unintended consequences also include the fact that people under a DoLS are viewed as being deprived of their liberty by the state and as such give rise to an automatic coroner’s inquest if they die while under DoLS. This has caused a huge burden on coroners and also on families and carers who endure significant emotional distress as a result.¹⁸

¹³ *HL v UK* 45508/99 (2004) ECHR 471

¹⁴ Mental Capacity and Deprivation of Liberty (Law Commission, July 2015)

¹⁵ *Cheshire West and Chester Council v P* (2014) UKSC 19

¹⁶ Dementia UK (Alzheimer’s Society, 2014)

¹⁷ NHS Digital, Mental Capacity Act 2005, Deprivation of Liberty Safeguards (England), Annual Report 2015-16, September 2016, data covers 1st April 2015 to 31st March 2016

¹⁸ An amendment proposed by Baroness Finlay to the Policing and Crime Bill will prevent this from happening but it is not known when this will come into force.

The CQC is responsible for monitoring the use of the DoLS in hospitals and care homes and reports on their use each year in their annual State of Care report.¹⁹ Inspectors now look at both DoLS and use of the wider MCA and the results inform ratings. In the most recent State of Care report (2015/2016), the findings demonstrated signs of improvement and pockets of good practice in relation to the implementation of the DoLS and the wider MCA. They noted particular improvements in adult social care.

Key challenges highlighted by the CQC in previous reports included the ‘unprecedented number of applications for authorisation’ caused by the *Cheshire West* case mentioned above. These challenges have continued with NHS Digital data showing that in 2015/2016, local authorities received 195,840 applications – up from 137,540 in 2014/2015.²⁰ There has also been an increase in the number of applications with urgent authorisations. The challenges now extend to providers of healthcare services outside of hospitals and care homes (for example supported living arrangements), who must apply to the Court of Protection to deprive someone of their liberty. 2016 also saw a rise in these types of applications. People who use services are affected by this situation, often subject to delays, not getting the right representation and consequently not getting care that is appropriate and consistent with their wishes.

Examples of good practice showed person-centred care, avoiding blanket assessments of capacity and taking into account the individual’s preferences. There were also clear policies and procedures in place to support implementation and staff understanding. All of these approaches are key for people with dementia to be given person-centred care that is as least restrictive of their rights as possible.

Care Act 2014²¹

The **Care Act** became law in April 2015 – it consolidated sixty years of law into one modern piece of legislation signifying a huge reform of the social care system in the UK. The Act has had significant implications for people with dementia and their carers. The Act was split into two parts. Part 1 came into force in April 2015 but the implementation of Part 2 has been delayed until 2020.

Part 1:

- Introduces the ‘**wellbeing**’ principle which local authorities must have regard to when planning and delivering services – wellbeing in this context includes physical, emotional and mental factors.
- Introduces a duty on local authorities to **assess anyone who may have care and support needs** – this extends to **carers** putting carers on an equal statutory footing as the people they care for.

¹⁹ Care Quality Commission (State of Care 2015/16, 27th October 2016)

²⁰ NHS Digital, Mental Capacity Act 2005, Deprivation of Liberty Safeguards (England), Annual Report 2015-16, September 2016, data covers 1st April 2015 to 31st March 2016

²¹ Care Act 2014

- Introduces a **national minimum eligibility threshold** – previously this was set locally – sets a minimum threshold for when local authorities must provide support.
- Duty on local authority **if asked to arrange care for anyone with eligible needs** (including self-funders)
- Duty on local authorities to provide a **care and support plan** for people with needs and a support plan for carers – this must be developed in consultation with the person, the carer or a family representative and must include a **personal budget – independent advocacy** must be available for people with no-one to act on their behalf.
- Responsibility on local authorities and partners to **integrate services** so that they are **joined-up**
- Duty on local authorities to ensure people can **move between local authorities without major disruption**
- **Safeguarding** is put on a statutory footing – local authorities must investigate where abuse or neglect is suspected. They must also establish a **Safeguarding Adults Board** which must publish an annual strategic plan and a report on the progress of this plan.

Part 2:

- Provides for a **capped cost system for care at home and residential care**
- **Increases the upper means test level** for people living in residential care

The Care Act has huge implications for people with dementia and their carers. It marks a shift towards putting people who have care needs at the centre of their care, puts carers on an equal footing with the people they care for and also provides legal grounding for protecting people who are at risk of abuse. It also emphasises the importance of involving people in the process of arranging care and provides for advocates if a person is unable to participate in the process themselves. The principle of wellbeing also requires local authorities to look at a person's whole situation (beyond just their physical needs) by including emotional and mental wellbeing across all aspects of a person's life as important. The Care Act also places safeguarding on a statutory basis for the first time.

Many of the provisions in the Care Act reflect greater personalisation in adult social care. This can also be seen in the development of healthcare policy (see NHS Five Year Forward View below). However, these aspirations are not always followed in practice, particularly for people with dementia. Alzheimer's Society conducted a mystery shopping evaluation of 60 local authorities with adult social services responsibilities in England. The investigation uncovered a worrying lack of information and support – **nearly two thirds of local authorities failed to provide information relevant to people with dementia**. In some instances, **local authority staff actively discouraged use of personal budgets for people with dementia**. **This research shows that although the Care Act provides for things that could be beneficial to people with dementia, they are not necessarily being implemented on the ground.**

3. BROADER HEALTH AND SOCIAL CARE POLICY

Health and Social Care Act 2012 (came into force in April 2013)²²

In 2012, the **Health and Social Care Act** was passed, providing for the biggest restructure of the NHS since its inception in 1948. The Act had huge implications for the way healthcare was commissioned and provided, abolishing Primary Care Trusts (PCTs) and Strategic Health Authorities (SHAs) and replacing them with Clinical Commissioning Groups (CCGs), which are predominantly GP-led. The Act also created Public Health England (PHE), the body responsible for improving the public's health and wellbeing and for addressing health inequalities.

NHS Five Year Forward View (published October 2014)²³

Following the structural changes to the NHS created by the Health and Social Care Act, the **NHS Five Year Forward View (FYFV)** was published in October 2014. This set out the long-term vision of the NHS and its strategic direction for the following five years. This signified a greater focus on integrated and personalised care, increased localisation and devolution and encouraged new models of innovative care. Three key arguments were put forward for the need for the strategy set out in the FYDV:

1. Need to radically **enhance prevention and public health promotion** to improve health of future children, ensure sustainability of NHS and economic prosperity
2. Patients should get **greater control of their care** – improved partnerships with voluntary organisations, development of shared personal budgets and greater support for unpaid carers
3. NHS needs to **break down barriers between how healthcare is provided** – including between physical and mental health, health and social care and across different settings such as GPs and acute hospitals - this argument allows for the development for new models of care that are locally developed to fit the needs of the particular community

Part of delivering the FYFV was the creation of new models of care which would be developed in various vanguard sites across the country. These sites are designed to act as 'blueprints' for the improvement and integration of services set out in the FYFV.

End of life care

In terms of specific areas of healthcare development, end of life care is an area that has moved forward since the publication of the Declaration. Although not one of the seven main 'I' statements, there is a sub-statement under number 1 which states: *"I will die free from pain, fear and with dignity, cared for by people who are trained and supported in high quality palliative care."*

The Government published an End of Life Care strategy in 2008. However, since 2013 end of life policy has been dominated by the controversy and subsequent withdrawal of the Liverpool Care

²² Health and Social Care Act 2012

²³ Five Year Forward View (NHS England, October 2014)

Pathway (LCP). In June 2014, the Leadership Alliance for the Dying Person came together and produced *One Chance to get it Right*, which contained the five priorities for care. NICE have drawn on these priorities to produce a new clinical guideline for caring for dying adults (December 2015) and are currently developing an accompanying Quality Standard. In July 2014, the Government commissioned Claire Henry (CEO of NCPC) to conduct a review of choice in end of life care. The 'Choice Review' was presented to the Government in February 2015 and they responded in July 2016 with 'the Commitment.' This is now the key government policy document driving forward improvement in end of life care.

As well as this, Ambitions for Palliative Care was published in September 2015. This provided a framework for making end of life care a priority at a local level given the changes signified by the Health and Social Care Act 2012.

People with dementia and their carers experience significant barriers to accessing good end of life care and achieving the ambition set out in the sub-statement.²⁴ Because dementia is progressive and prognosis is uncertain, it can be hard for people with dementia to access palliative care services. Lack of understanding of the symptoms of dementia (including difficulties with communication) and inadequate staff training can mean that a person is not identified as being near the end of life, or that their particular needs (such as nutrition and pain relief) are not addressed. Many end of life services have been and remain dominated by a model that fits better with cancer, which means that people with dementia do not necessarily get care that is personalised to their condition and their needs. As dementia affects capacity as it progresses, it is important that they are supported to express their preferences and choices for end of life care early, but this can be difficult to do in practice. A lot of discussion around achieving good end of life care centres on place of death – people with dementia are much more likely to die in a care home and much less likely to die in a hospice.²⁵

The influence of 'rights'

Social model of disability

Increasing influence of rights in the context of dementia has in part been due to a greater focus on the **social model of disability**. Understanding dementia from the perspective of the social model has implications across all areas of dementia policy including how services are designed, how people with dementia are involved in their care and in wider decision-making and also how to address cultural, societal and institutional attitudes towards understanding and awareness-raising of dementia.²⁶

²⁴ Living and dying with dementia in England: Barriers to care (Marie Curie and Alzheimer's Society, December 2014); A different ending: inequalities in end of life care (Care Quality Commission, May 2016)

²⁵ Dying with dementia, (Dementia Intelligence Network, September 2016)

²⁶ Joseph Rowntree Foundation, *How can and should UK society adjust to dementia?* Carol Thomas and Christine Milligan, June 2015

Adopting the social model encourages researchers and policy-makers to look more closely at the everyday experiences and perspectives of a person with dementia rather than the purely biological fact that the person has the condition.

UN Convention on the Rights of Persons with Disabilities²⁷

The **UN Convention on the Rights of Persons with Disabilities (CRPD)** was adopted in 2006 and ratified by the UK in 2009. The Convention provides for the promotion and protection of the human rights of people with disabilities and includes many areas relevant to people with dementia. These include:

- Capacity and decision-making (Article 12)
- Non-discrimination
- Inclusion and participation in society
- Accessibility
- The ability to live independently

Alzheimer Europe have described Article 12 of the CPRD as a ‘paradigm shift’ away from a caring protectionist approach to people who may lack capacity to one that focuses on an individualistic approach centred on self-determination.²⁸

The UN Committee on the CRPD published a report on their inquiry into the UK in November 2016. The investigation was conducted following concern from organisations within the UK about the impact of welfare cuts on disabled people. This report was critical of many aspects of welfare policy relevant to people with disabilities including discriminatory impact on disabled people’s ability to live independently, inadequate consideration of the impact on disabled people in designing policies, negative portrayal of disabled people in the media and predominance of a medical approach to welfare assessments.²⁹

International

International dementia policy and campaigning has also started to use a more rights-based approach. On the UN International Day of Disabilities (3rd December) in 2015, **Alzheimer’s Disease International (ADI)** and **Dementia Alliance International (DAI)** joined together to call on dementia to be recognised as an invisible disability.³⁰

In a briefing jointly compiled by the two alliances, they stated that despite dementia undeniably falling within the definition of disability put forth by the CRPD, it has not been included by member

²⁷ United Nations Convention on the Rights of Persons with Disabilities (December 2006)

²⁸ Dementia in Europe Yearbook 2016 – Decision making and legal capacity in dementia, Alzheimer Europe: <http://www.alzheimer-europe.org/Publications/Dementia-in-Europe-Yearbooks>

²⁹ The report can be found here: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeCategoryID=7

³⁰ UN International Day of Persons with Disabilities - Dementia an invisible disability <https://www.alz.co.uk/news/un-international-day-of-persons-with-disabilities-dementia-invisible-disability>

states in their implementation of the Convention nor has the CRPD been included in the dementia strategies of 26 member states and two regions. They state that:

“The greatest single obstacle to the continued participation of persons with dementia in society arises from the stigma and fear of dementia in the general population and under-estimation of their capacity by politicians, professionals, researchers and the community.”³¹

The results of this discrimination are far reaching – people with dementia are frequently left undiagnosed or uninformed of their diagnosis, left without access to adequate treatment and support services and socially isolated and stigmatised. The CRPD articles cover many areas relevant to improving the quality of life for people with dementia including awareness-raising, improving accessibility, ensuring an adequate standard of living, non-discrimination, use of restraint, enhancing capacity and supported decision-making. It also refers to involving people with dementia in decisions and policies.

Prior to issuing this briefing, the ADI Council and Board agreed to pursue the recommendations set out in a policy paper of April 2016, which examined how the CRPD applied to people with dementia and how it could be used as a tool for change.³² This paper argued that the CRPD should be used as part of a ‘suite of advocacy strategies’ to protect the human rights of people with dementia including the creation of dementia-friendly communities, development of national strategies for dementia and inclusion of dementia in the UN 2016-2030 Development Goals. The paper asserted that:

“The use of the CRPD as a tool for social change could be particularly useful in countries where the stigma associated with dementia is strong and more generally to achieve practical outcomes in access to health and everyday services, reduction in the use of restraints and anti-psychotic medication and the availability of high quality social care and support.”³³

The development of the **Mental Capacity Act (Northern Ireland)**³⁴ provided the first opportunity for creating legislation in this field since the ratification of the CRPD. The approach taken by the Act in Northern Ireland is one that moves away from the stigma engendered by having separate legislation for when a person has a particular condition. The Act places greater emphasis on supported decision-making and on using the person’s wishes and feelings to guide best interests assessments. The basis for the Northern Ireland Act was the Bamford Review of Mental Health and Disability, which proposed a comprehensive new legislative framework for fusing mental health and mental capacity legislation.³⁵

³¹ Access to CRPD and SDGs by Persons with Dementia (Alzheimer’s Disease International, August 2016)

³² Harnessing the United Nations Convention on the Rights of Persons with Disabilities to improve the lives of persons with dementia, (Alzheimer’s Disease International, April 2016)

³³ *ibid*

³⁴ Mental Capacity (Northern Ireland) Act 2016

³⁵ A Comprehensive Legal Framework for Mental Health and Learning Disability, August 2002, <https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/legal-issue-comprehensive-framework.pdf>

Mental capacity case law

The emphasis on individual rights and preferences can also be seen in case law development under the Mental Capacity Act predominantly in the context of best interests decisions. Although not solely concerned with dementia, the approach taken by the courts signifies a shift in healthcare towards placing greater emphasis on the person's wishes and less emphasis on solely objective clinical factors. The key case in this area was ***Aintree***, which reached the Supreme Court and concerned the decision whether it would be in a person's best interests to continue to receive life-sustaining treatment.³⁶ In making the decision, the court considered that the concept of best interests went beyond purely medical decision-making and in fact required the person's welfare to be considered in a more holistic way, which took into account his views on quality of life, likes and dislikes – it required the healthcare team to put themselves in the position of the patient and view the proposed intervention in the way that they would do.

A clear demonstration of a rights-based approach in this area of law was Lady Hale's judgment in ***P v Cheshire West and Chester Council***, the leading DoLS case. The first question she had to answer in this case was whether 'deprivation of liberty' means the same for disabled people and non-disabled people. She firmly stated that it does and that their 'universal character' was the 'point of human rights.'

³⁶ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67