



Mental Health  
Foundation

# **Dementia, rights, and the social model of disability**

A new direction for policy and practice?

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## Summary



Viewing dementia as a disability in terms of the social/rights-based model and the way in which people living with dementia are responded to has a range of implications.

This paper describes the social model of disability in relation to dementia, as well as national and international law that is informed by it or that it connects with. It goes on to describe tools that can be used to apply the model through policy, practice, service and community development. Using the social model of disability has implications for the rights of people with dementia under the law, for disability discourse and public policy, and for how dementia is experienced and perceived by people with dementia and their carers, as well as how it is viewed and discussed in public.

There are several implications for dementia policy and practice/services. In the social model, people with dementia are centre stage, with their voices elevated, and are recognised as equal citizens with rights. They are the agents of change and their agency is valued and recognised.

They are part of mainstream society and the range of barriers (social, attitudinal, physical and environmental) that oppress and exclude them are broken down. They are also part of a broader social movement for global change. A current manifestation of the social model in practice is the development of dementia-friendly communities. Tools have been developed to enable the adoption of a rights-based approach and these can be effectively used in developing dementia policy and practice.

However, moving towards a social model requires massive change at the micro and macro (individual, institutional and systemic) levels. There are many stakeholders involved and their roles in this model change significantly and a shift in the power dynamics is necessary. Societal change is also needed in the form of a shift from the current 'medicalised' perspective on dementia to one that is based on the principles of solidarity and inclusion. The debate has really only just started.

### Keywords

Dementia, disability, social model, human rights, law, rights-based approaches

## About this report



This report has been produced by the Mental Health Foundation in a project that was funded by the Joseph Rowntree Foundation.

In order to produce the report, the Mental Health Foundation consulted extensively. This included consulting with an expert advisory group (involving people with dementia and carers) and a roundtable event held in London in March 2015. Thirty-five people attended the event and the audience included people with dementia, carers, disability activists, legal experts and academics, and representatives from government and third sector organisations (see Appendix A for a programme of the event).

Participants at the event heard presentations from people with dementia and disability activists; both the expert advisory group and participants at the roundtable event (as well as people who were invited but unable to come) contributed their views and comments on earlier drafts of the report and on the issues it raised more widely. The event took place under 'Chatham House Rules' (i.e. everything said at the event would be reported anonymously in order to encourage people to talk openly), but a summary of comments is contained in Appendix B.

Innovations in Dementia (iD), a community interest company that works closely with people with dementia to support them in having their voice heard, assisted the project in order to ensure the meaningful involvement of people with dementia. iD have also produced a key points summary of the paper, which is available at: [www.mentalhealth.org.uk/publications](http://www.mentalhealth.org.uk/publications)

### **Recommendations**

The report does not contain specific recommendations, but sections 7 and 8 identify a number of areas where organisations and other stakeholders in the field of dementia can apply a rights-based approach and the social model of disability in policy, practice, service, and community development. Appendix B also contains possible areas for action that emerged from the roundtable event held in March 2015.

# Acknowledgements



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# 1. Introduction



Dementia discourse has historically been dominated by a highly 'medicalised' notion of dementia: as a disease associated only with irreversible decline and deficits and where 'nothing can be done'. However, there has been a recent shift in the discourse.

Dementia is increasingly being viewed as having a rights-based dimension. This has a number of benefits, including greater legal protection, entitlement to services, and a positive cultural shift in the way that dementia is perceived and understood (including by people with dementia themselves). There are a range of contributory factors to the shift in tone and emphasis in the dementia discourse, including the elevation of the voice of the person with dementia, the social model of disability and the emergence of rights-based initiatives in the dementia landscape. Some national and international legislation also provide a framework in supporting this shift.

## Key questions addressed

The debate on viewing dementia as a disability is new for some. Engaging people with dementia, their families and friends, and those working in the dementia field in a human rights discourse is new for many. This paper is an attempt to pull together some of the core issues that relate to opening up a dialogue on dementia as a human rights issue and the implications of the social model of disability. It addresses some key questions:

Is there merit in viewing dementia as a disability by using the social model of disability, and what are the issues to consider? What are the possible implications for dementia policy discourse and service provision? What are the implications for people living with dementia and their human rights? What is the role of national and international law?



## **What is dementia? A common definition**

Dementia is an umbrella term for a range of conditions that cause damage to the brain. This damage can impact on a person's memory, thinking, language and their ability to carry out everyday tasks. There are many conditions that cause dementia. Alzheimer's disease is the most common, but there are many others, including vascular dementia, Lewy body dementia and fronto-temporal dementia. Each person's experience with dementia is unique. There are 850,000 people with dementia in the UK.

There is no cure for dementia and there are no universally accepted, effective treatments available. However, there are medications, services and methods of support that can help people to live well. The risk of developing dementia increases with age; it affects one in 14 people over the age of 65, but one in six people aged over 80. As an 'ageing society' with more people living longer, it is estimated that there will be over a million people in the UK living with dementia by 2025. Two thirds of people with dementia live in their own homes and one third, usually those with more severe or advanced dementia, live in care homes.

However, conventional ways of defining and describing dementia draw largely on medical and clinical language and often problematise it in terms of ageing demographics. Throughout the course of this paper, the contention is that dementia can also (or alternatively) be conceptualised and described differently, using a social model of disability approach. It argues that people with dementia have a range of impairments and, as a result, face a variety of disabling barriers, including attitudinal, social, psychological, architectural, physical and institutional. Such barriers have led to their marginalisation, exclusion, and oppression.

### **Sources:**

Age UK (2014) Later Life in the UK factsheet, Alzheimer's Society (2014) Dementia 2014 infographic:

<http://www.alzheimers.org.uk/infographic>;

<http://www.alzheimers.org.uk/statistics>; Mental Health Foundation:

<http://www.mentalhealth.org.uk/help-information/mental-health-a-z/D/dementia/>.

## 2. Dementia, disability and rights – an overview



At present, dementia is not readily recognised as a disability in policy and practice terms and, therefore, is a relatively unexplored area that has limited evidence or experiences available to draw on, with some notable exceptions (see, for example, Gwilliam & Gilliard 1996, Bartlett 2000, Downs 2000, Gilliard et al 2005, Mittler 2012, Donnelly 2014, Thomas & Milligan 2015).

Rarely are the words 'dementia' and 'rights' put together in contemporary debates or discussions on dementia. People with dementia are not at the fore in mainstream human rights debates in the same way as other marginalised and oppressed groups are in society. However, anecdotal evidence suggests that some national dementia organisations are using disability/human rights laws to address the rights issues that people with dementia are facing (for example, in employment issues and entitlements to health and social care services). Organisations are also using the relevant legislation to challenge decisions that are being made by service providers and agencies if they are denying people access to services on the basis of a dementia diagnosis alone.

It is important to note that the rights enshrined in national and international human rights law and conventions are 'diagnosis neutral', i.e. they do not distinguish between different illnesses and conditions. Not only would this make legislation far too complicated but, more importantly, it would be discriminatory, as well as unnecessary. Instead, it uses the language of 'disability' – the physical, psychological and cognitive impairments that arise from illnesses, diseases

and health conditions – and how individuals and organisations must ensure that people with these impairments are not excluded or treated unfairly, and can be accommodated in the same way as non-disabled people.

Securing these rights in law has been a long and difficult struggle and people with physical disabilities, learning disabilities and mental health problems have all been involved in lobbying for change. They have demonstrated what can be achieved through activism and campaigning. In these debates, and in the legislation, disability has been framed in terms of the 'social model of disability' – that society must adapt to enable the participation of disabled people as equal citizens.

'Disability' is therefore a means to an end, not a negative, pejorative or stigmatising label to be imposed upon individuals. Nor is the term 'disability' in this context intended to focus on what a person can't do, but rather the wider societal context in which a person with a disability lives their life and what they can do. National laws and policies (e.g. mental capacity legislation, health and social care services, dementia-friendly communities, etc.) must be compliant with human rights legislation – disability rights are therefore potentially powerful levers for change.

The social model of disability, the disability rights movement and how these may impact on dementia policy and practice are described in greater detail in the following sections of the paper. First, the paper explores how the current laws are relevant to people with dementia in realising their human rights.

## 3. National and international law



### 3.1 Legislation

People with dementia have the same civil and legal rights as everyone else. The Human Rights Act 1998 (HRA) and European Convention on Human Rights apply to everyone. Dementia is a disability under UK disability legislation (the Equality Act)<sup>1</sup> and human rights laws, and under the United Nations Convention on the Rights of Persons with Disabilities (CRPD). This means that people with dementia are protected by law from some kinds of discrimination: in employment and in their use of goods and services (including health and social care services).

#### The Equality Act 2010

The Equality Act 2010 defines disability as a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on a person's ability to do normal daily activities. According to this definition, mid-late stage dementia (where the symptoms are more severe) clearly falls within the scope of the Act and, therefore, people living with dementia should receive full protection under the Act against all forms of discrimination that are unlawful under it, based upon their disability, including 'reasonable adjustments' by employers and the providers of goods and services. For people in the early stages of

dementia, there is an argument that people have a right to decide for themselves when it begins to have a 'substantial' and 'long-term' negative effect and, therefore, when they become 'disabled' by, or rather by virtue of, their dementia.

The Government's Office of Disability Issues Equality Act guidance states that: "A disability can arise from a wide range of impairments which can be:

- sensory impairments, such as those affecting sight or hearing;
- impairments with fluctuating or recurring effects, such as rheumatoid arthritis, myalgic encephalitis (ME), chronic fatigue syndrome (CFS), fibromyalgia, depression, and epilepsy;
- progressive, such as motor neurone disease, muscular dystrophy, and forms of dementia.

#### Mental capacity legislation

Mental capacity legislation also has a role in enforcing rights for people with disabilities who are cognitively impaired. For example, the Mental Capacity Act 2005 (MCA) that covers England and Wales<sup>2</sup> can be seen as an empowering piece of legislation that supports the rights of people to make decisions for themselves wherever possible. However, as the House of Lords

1. The Equality Act covers England, Wales and Scotland but has not yet been extended to cover Northern Ireland.

2. Scotland has its own mental capacity legislation: the Adults with Incapacity (Scotland) Act 2000. Northern Ireland does not currently have specific mental capacity legislation.



Select Committee on the MCA reported, it has also been used in ways that reinforce overly protective, risk-averse cultures in health and social care that undermine autonomous decision making and self-determination.<sup>3</sup> Mental capacity legislation is currently being reviewed as part of the UK requirement to report on compliance with the CRPD in 2016 (see page 9).

## The Human Rights Act 1998 and the European Convention on Human Rights

The Human Rights Act 1998 (HRA) provides the UK with a legislative framework to implement the European Convention on Human Rights (ECHR).<sup>4</sup> The UK helped draft the ECHR, which is a European codification of the Universal Declaration of Human Rights that was adopted by the United Nations in 1948 in the aftermath of World War II. The ECHR rights apply to everyone, and laws, government policy, and the decisions, actions and behaviour of government and public authorities (including the NHS and local government) must be compliant with the ECHR. The HRA gives the ECHR the full force of law in the UK and enables people to take cases under the ECHR to British courts (which can subsequently be referred to the European Court of Human Rights).

A range of ECHR articles are very applicable to supporting people with dementia to have their rights upheld. Five articles are of particular relevance:

- **Article 2** – the right to life (with virtually no exceptions)
- **Article 3** – prohibits inhuman or degrading treatment or punishment (with no exceptions or limitations)
- **Article 5** – everyone has the right to liberty and security of person (subject to lawful arrest or detention, which can include people with mental disorders)
- **Article 8** – the right to private and family life (subject to certain restrictions that are “in accordance with the law” and “necessary in a democratic society”)
- **Article 14** – freedom from discrimination, including on the grounds of disability (but only in respect to the person’s rights under the Convention).

It was as a result of a case taken to the European Court under Article 5 (the ‘Bournemouth Gap’ case) that the Mental Capacity Act was amended with the addition of the Deprivation of Liberty Safeguards (DoLS), which provide legal protection for people who need to be detained in hospitals or care homes for care and treatment but lack the capacity to consent to this.

3. House of Lords Select Committee report on the Mental Capacity Act 2014.

4. It should be noted that, at the time of writing, the newly elected Conservative Government stated that it intends to repeal the Human Rights Act and replace it with a “Bill of Rights”; however, this would still need to be compliant with international human rights law that we are signatory to, such as the ECHR and the CRPD.



## The Care Act 2014

The Care Act 2014 (which came into force in April 2015) is (potentially) very relevant for people with dementia and their carers to consider in terms of securing their rights.<sup>5</sup> The Act brings together existing local authority responsibilities for providing social care into a single piece of legislation, as well as some new responsibilities. Its overarching principle is one of individual wellbeing.<sup>6</sup> The legislation outlines the domains of wellbeing that it is concerned with, including personal dignity, protection from abuse, control by the individual over their day-to-day life, physical health, mental health and emotional wellbeing, and the individual's contribution to society. These domains are a direct reflection of the social model of disability principles. The Care Act obliges local authorities to enable the individual to participate as fully as possible in decisions about them and to be provided with the information and support necessary to do this, and to ensure that any restriction on the individual's rights or freedom of action is kept to the minimum necessary. In the statutory guidance to the Act, the Department of Health also states that the wellbeing principle is intended to cover Article 19 of the United National Convention on the Rights of People with Disabilities. It could be argued, therefore, that the Act provides a way for people affected by it (including people with dementia) to ensure that their entitlements under the Act are backed up by the CRPD. However, it remains to be seen whether it is used in this way.

## United Nations Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities (CRPD) is an international treaty that was passed by the United Nations in 2006. The CRPD promotes and protects the rights of the person with a disability. It aims to ensure their enjoyment of human rights and equality under the law and represents a legal framework for applying generic human rights legislation in a way that is meaningful for people with disabilities. It is far-reaching and calls for fundamental change in terms of society's approach to understanding and responding to disability. Its sentiment revolves around ultimately eradicating any sense of difference in society between disabled and non-disabled people (although paradoxically, but perhaps necessarily, it still has to use a concept of disability to achieve this). The UK has ratified the CRPD, which means that national laws and government policies should be compliant with it.

As an instrument, the CRPD uses a social model of disability and defines disability as including "those who have long-term physical, mental, intellectual or sensory impairments in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others". People living with dementia should also be afforded the protections available under the CRPD and, therefore, it has significant relevance and meaning and can shape the field of dementia at the

5. The Care Act only applies in England. Scotland, Wales and Northern Ireland are all in the process of amending their respective social care legislation and all of them are including a wellbeing principle.

6. It should be noted that the concepts of wellbeing and personhood in dementia were developed extensively by Tom Kitwood (1997) in his seminal work 'Dementia Reconsidered' (which briefly refers to the social model of disability in relation to dementia on p.46). Kitwood's frameworks involving these concepts continue to inform the narrative of people with dementia (see Appendix C).



**Table 1: Key CRPD Articles for people with dementia**

<b>Relevant Article</b>	<b>Title</b>	<b>The right to (on an equal basis with non-disabled people)...</b>
<b>3</b>	General principles	Respect for dignity and autonomy, non-discrimination, participation and inclusion, respect for differences, equality of opportunity, accessibility, gender equality.
<b>4</b>	General obligations	General duties to promote the CRPD through legislation, practice, research, training, etc.
<b>9</b>	Accessibility	Access environments, transport, information, services.
<b>12</b>	Equal recognition before the law	Enjoy legal capacity on an equal basis with others in all aspects of life. Supported decision making that respects the person's autonomy, will and preferences.
<b>13</b>	Access to justice	Use the judicial system.
<b>19</b>	Living independently and being included in the community	Choose place of residence. Access to community support to live and remain in the community. Services for general population which are inclusive of people with disabilities.
<b>20</b>	Personal mobility	Mobility support to be able
<b>25</b>	Health	Good health and health services
<b>26</b>	Habilitation and rehabilitation	Rehabilitation, reablement and support services.
<b>27</b> <b>28</b> <b>29</b> <b>30</b>	Work and employment Adequate standard of living and social protection Participation in political and public life Participation in cultural life, recreation, leisure and sport	Comprehensive access to services, including work, adequate standard of living, participation in civic life, culture/recreation/sport.

global and local levels. There is now a United Nations open-ended working group looking at developing a convention on ageing/older people which will have relevance to people with dementia (although, this in its own right may be discriminatory because 'old age' is difficult to define and a significant number of people with dementia develop the condition earlier in life). Appendix Table 1 highlights some of the most relevant sections of the CRPD (it also includes Articles similar to those in the ECHR).

The legal rights of people living with dementia are relatively unexplored, apart from some modern legal capacity legislation. However, even capacity legislation is not without its issues. At present, the MCA is deemed to be non-compliant with international law, in the form of the CRPD, although it is unclear if there are any existing mental capacity legal frameworks in the world that are fully compliant. This is partly because the CRPD requires a totally supported decision-making legal regime which poses significant challenges in terms of operationalising this for people with very severe dementia and those with profound learning disabilities. This purist legal stance of supported decision making in the CRPD is a real issue for disability activists to address and needs further debate to address the nuances. It also appears that the CRPD outlaws discrimination based upon diagnostic categories (such as 'mental disorder or impairment') which means that not only are mental health and mental capacity legislation non-compliant, but so too is the ECHR itself (which uses the concept of "unsound mind"! ). The Essex Autonomy Project at Essex University<sup>7</sup> provides further detail.

It will take time to build a body of test cases and case law to create precedence in the field of dementia, in particular. This process will potentially open up a range of possibilities for people with dementia and those supporting them to explore an explicit expression of what their rights are in national and international legislation. Instead of perceiving national and international law as abstract or irrelevant concepts in their lives, people with dementia could embrace them as relevant drivers of change, locally and nationally, to improve their lived experience, tackle exclusionary barriers and get recognition as people with rights.

It is also appreciated that law making, while a valuable instrument, is only one aspect of the transformative change that is needed. Legislation is not the panacea but is certainly a major catalyst to drive institutional and systemic changes.

### **3.2 Legal rights, rights-based approaches, and rights to services**

As discussed, people with dementia need instruments of the law, procedures and mechanisms of redress to secure their rights. Equally, rights-based initiatives, which enshrine human rights principles, can drive change in dementia policy and practice. See Table 2 for examples of both.

There is also a more common perception and understanding of people's 'rights' in relation to entitlement to public services. Many people believe that rights to health and social care are the same. They are not, and they also vary across the UK. While there is a universal right to free healthcare at the point of need in the UK, rights to

7. <http://autonomy.essex.ac.uk/mca-compliance-with-the-uncrpd>.



publicly funded social care, housing, and welfare benefits, are more conditional rights that depend upon the financial situation of the individual, severity of need, etc.<sup>8</sup> However, any legislation relating to these entitlements must be compliant with human rights legalisation. The Scottish Government's Post-Diagnostic Support guarantee, entitling anyone diagnosed with dementia in Scotland to a year's post-diagnostic support, is an example of applying a rights-based initiative to dementia policy and practice. It also serves to illustrate the variations in the development of policy for people with dementia across the UK.

Access and entitlement to services for people with dementia should be compliant with the human rights legalisation (including the CRPD) but, as already indicated, this compliance remains largely

untested. However, as already pointed out, recent changes in social care legislation across the UK may provide opportunities to test this compliance with the CRPD. The Scottish Charter of 'Rights for People with Dementia and their Carers' is a description of how the human rights and the CRPD should apply to people with dementia and their carers. The UK is due to report its compliance with the CRPD to the United Nations in 2016, so this will provide an opportunity to consider in more detail the relationship between legal rights as defined by the CRPD, rights-based approaches, and people's experience of securing their entitlement and access to services. However, a further aspect of this is the variation in the manner or degree of implementation of the CRPD in the four main UK jurisdictions, and the lack of central co-ordination and progressive realisation of human rights under the CRPD.

8. It should be noted that, depending usually upon the severity of the dementia, people may be entitled to free NHS 'continuing care', means-tested local authority social care, or a combination of both.



**Table 2: Legal rights and rights-based approaches relevant to dementia**

**Examples of legal rights in the UK and international legislation relevant to people with dementia**

European Convention on Human Rights (ECHR), ratified by the UK in 1951

International Covenant on Economic, Social and Cultural Rights, International Covenant on Civil and Political Rights 1966

Human Rights Act 1998 (HRA)

Adults with Incapacity (Scotland) Act 2000

Mental Capacity Act 2005 (MCA)

UN Convention on the Rights of Persons with Disabilities, 2006 (CRPD)

Equality Act 2010

Care Act 2014 (and equivalent legislation in Scotland, Wales, and Northern Ireland)

**Examples of rights-based approaches in dementia**

The universal right to free healthcare at the point of need (UK)

Charter of Rights for People with Dementia and their Carers (Scottish Government)

I have dementia...I have rights (The Alzheimer Society of Ireland)

Scottish Dementia Working Group/European Working Group of People with Dementia

Dementia Engagement and Empowerment Project (DEEP network)

No Limits: Re-imagining Life with Dementia (the University of Southampton, the University of Bradford)

Dementia-Friendly Communities

## 4. The social model of disability



### 4.1 The development of the disability rights movement

The social model of disability provides a crucial framework to discuss the rights of people with dementia and underpins national and international legalisation on disability, most notably, the Equality Act and the CRPD. Therefore, an understanding of this model is needed.

The disability rights movement had its genesis in the USA in the early 1970s, when people with disabilities came together to discuss the issues in their lives and their experience of exclusion from mainstream life. The movement gathered significant support from disabled people and it spread across the UK and Europe in the 1980s, often with the support of non-disabled people and professionals. It is now a well-established global movement: one that has been described as the “last civil rights movement” (Driedgner, 1989).

In the UK, notable successes have been the role that disabled people have played in challenging long-term institutional care, the campaign for the Disability Discrimination Act (now part of the Equality Act), the development and implementation of direct payments and personal budgets and, more generally, the increased public visibility of people with disabilities in many different walks of life.

### 4.2 Medical model versus social model

Disabled people, as part of the movement, began to describe their experiences of living with a disability and coined the phrase ‘medical model of disability’ to explain how they were being prevented from making choices, exercising control and being active citizens. The medical model was used by the disability rights movement to explain disabled people’s exclusion from mainstream social and economic life, their oppression (especially through the use of institutional care) and their lack of recognition as having basic human rights. It explained how barriers to participation were erected and maintained. At the opposite end of the spectrum, the ‘social model of disability’ emerged as the disability rights movement’s response to the medical model and embodies what disabled people want to be: empowered citizens with rights and the ability to live a life of their own choosing.

In the medical model, it is the person’s disability (i.e. their condition) that is the problem. Decisions are made for people by others (professionals, non-disabled people, etc.) who claim to know what is best. The person has very little control, very little power and very few choices (or none at all), and has only a limited role in making decisions about their own lives (or no role at all). The medical model maintains oppression, exclusion and passive dependency of the person.

The social model of disability, which was developed and framed by the disability rights movement from the 1970s onwards, argues that the person has an impairment (as a result of a condition) and that they are disabled not by their impairment, but by a broad range of social, economic, attitudinal, physical, architectural and environmental factors. Therefore, the solution to addressing disability resides in bringing about change in these environmental factors, rather than trying to change largely unalterable individual characteristics of the impairment (DeJong, 1979). The disability movement adopted this radical definition of disability, with the disabling factors stemming only from the environment. However, in the late 1990s, a variation of this model was proposed that gave greater credence to the personal experience of having a disability, in conjunction with the political and social contexts (Marks, 1999). In this arguably less radical model, bodily function, emotional state and lived experience were also seen to be important, as well as 'impairment effects' (Thomas, 1999). This variation on the social model has been set out in the Vienna Declaration and Programme of Action of the World Conference on Human Rights 1993, Section 6 (United Nations).<sup>9</sup>

Given that the majority of people with dementia frame dementia as an illness or disease (with some rejecting the concept of it being a disability because of the negative connotations this can imply), a more nuanced and less radical model of disability may be more appropriate to engage. It can certainly be argued that the lived experience of people with dementia is usually articulated as the impairment itself causing a disability. Therefore, a

disabling factor may be intrinsic to the condition. In these instances, the social model needs to take account not only of the external barriers, but also of the social and psychological obstacles that exclude or restrict full participation in society. Lived experience, as well as societal responses, may also vary significantly depending on the severity, perceived 'stages', and the type of dementia.

Leaving these issues aside, it is certainly the case that, as a result of four decades of activism, the majority of contemporary policy and law making, as well as professional practice in relation to people with disabilities, are based on the broad tenets of a social model of disability and rights-based perspectives. Nevertheless, in reality where this is most embedded is in the lives of people with physical disabilities and learning disabilities and, even here, there remain ongoing struggles to ensure that legal rights are properly respected and applied.

At the core of the social model of disability is a (human) rights perspective. However, the human rights lens has not been widely applied in relation to the lived experience, the policy response or the services that are provided to people with dementia. People with dementia frequently reside in the medical model with others – in particular, clinicians – who often make decisions on behalf of the individual, prescribe a treatment regime (often only pharmacologically focused) and retain (perhaps sometimes unintentionally) the power in the relationship; thereby, the person with dementia is often rendered a passive dependent.

9. The model is discussed in detail in Kayess and French (2008) and is discussed in relation to dementia in Bartlett (2000).



Nevertheless, it is important not to discount the perspective that many people with dementia (and their families) have of viewing dementia as a disease/condition and seeking out medical solutions, or discount their need to have access to appropriate health and social care services. The social model contests the way in which policy is developed and services are delivered.

It should also be noted that a significant number of people with dementia in the UK are not diagnosed, some may not have the diagnosis revealed to them or may not

be able to understand it, and some do not wish to disclose their diagnosis for various reasons, including the stigma that is often attached to dementia. This adds further complications to the implementation of rights legislation based upon identifying an individual as a person with a disability. However, the social model and legislation based upon it is still relevant and useful for people with dementia, even if they do not necessarily define it as a disability.

Table 3, illustrates how the medical and social models would look in relation to people with dementia.



**Table 3: Medical model versus social model from the perspective of people with dementia**

Medical model	Social model
The problem is contained within the individual; dementia is about deficits – what’s the cure?	Social, attitudinal and architectural environments are the barriers to an individual’s participation
A person with dementia is not involved in decisions: decisions are made for them	A person with dementia is at the centre of the decision-making process (and is supported in this way)
A person with dementia has no responsibilities, no control and is disempowered	A person with dementia is responsible, has control and is empowered and self-determining (facilitated by the appropriate support)
People with dementia are charity cases in need of sympathy; they are victims and are objectified	People with dementia have human rights, are deserving of dignity and respect, and are active subjects
People with dementia are passive dependents	People with dementia are active citizens
Policy and services responses largely paternalistic and oppressive	Policy and services responses as tools of inclusion and active engagement
Power and control is outside the hands of people with dementia: it is with other stakeholders	Power and control in the hands of the individual with dementia

## 5. Applying the Social Model – the Human Rights-Based Approach and PANEL principles



To promote practical and systemic change in order to embed the social model of disability, a framework and process has been developed involving a tool used widely in social justice work called the Human Rights-Based Approach (HRBA). An HRBA presents a real opportunity to manifest the principles of the social/rights model of disability into practice. In order to deliver a HRBA in practice, five 'PANEL' principles were developed.<sup>10</sup>

**PANEL is an acronym that refers to:**

- Participation
- Accountability
- Non-discrimination and equality
- Empowerment
- Legality of rights

These principles (described in more detail in Table 4) are a key way in which an HRBA can be operationalised in practice. It is a tool that any practitioner, service provider or policymaker can use to examine whether they are putting human rights into practice.

An HRBA can be applied in many circumstances, including the developing of government policy, the allocation of funding by the state, the development of legislation, the way in which research is conducted and the way in which services are designed, delivered, monitored and evaluated.<sup>11</sup>

Using an HRBA and the PANEL principles has real potential to offer a practical tool in policy<sup>12</sup> development for people with dementia, as well as for practice and service development. They can be used in developing policy and practice at the macro (systemic) and micro (organisational/ stakeholder) levels.

Table 4 identifies the key questions that need to be addressed in terms of conducting an HRBA using the PANEL principles at the macro level.

10. Scottish Human Rights Commission: <http://www.scottishhumanrights.com/humanrights/humanrightsbasedapproach>.

11. Alzheimer Society of Ireland (2013)

12. Policy, in relation to people with dementia, not only includes health and social care but a whole range of other areas that impact on people's lives, including housing, transport, environment, employment, and income support.



**Table 4: Using the PANEL principles to implement an HRBA in dementia practice – the key questions (macro level)<sup>13</sup>**

Principle	Key questions to be addressed
<p><b>Participation</b>  <i>Everyone has the right to participate in decisions that affect their lives</i></p>	<p>Are people with dementia involved in the process/policy? Have any barriers to their involvement been identified and addressed?</p>
<p><b>Accountability</b>  <i>Effective monitoring of human rights standards and remedies for breaches</i></p>	<p>Who is responsible for the process/policy? Is there a way of assessing whether they have carried out their responsibilities? Is there a mechanism to hold them accountable?</p>
<p><b>Non-discrimination and equality</b>  <i>All forms of discrimination in the realisation of rights are prohibited, prevented and eliminated with priority given to the most vulnerable</i></p>	<p>Have individuals and groups of people with dementia been identified as being vulnerable to human rights breaches? How might the policy impact people with dementia? What can be done to be inclusive of people with dementia/lessen the negative impact of the policy?</p>
<p><b>Empowerment</b>  <i>Individuals and communities should understand their rights and be supported to participate in the development of policy and practices that affect their lives</i></p>	<p>What information will people with dementia who are affected by the policy/ decision need in order to be able to effectively influence the decision?</p>
<p><b>Legality of rights</b>  <i>Recognition of rights that are legally enforceable entitlements (linked to national and international law)</i></p>	<p>Is the approach explicitly grounded in human rights law? Does it follow the relevant principles of human rights law? If there is relevant legislation, does it comply? Is the legal framework explicitly stated so that rights holders can use it to bolster their claims?</p>

13. Adapted from the Alzheimer Society of Ireland (2013) and the Scottish Human Rights Commission: <http://www.scottishhumanrights.com/eqhria/eqhriaaddvalpolicy>.

## 6. Implications for policy discourse and service provision



Viewing dementia from the social model perspective has several implications for policymakers and service providers. It has implications regarding the principles underpinning both policy developments and service provision.

Dementia, as a disability, also provides an alternative framework to rethink and reimagine dementia as a rights, social justice and equality issue. This, in turn, opens up the policy focus beyond the narrow health and social care framework.

The social model of disability has the potential to lead the dementia discourse in a new and exciting direction. It reshapes how dementia is talked about and, critically, who does the talking. No longer would others talk for people with dementia when they can speak for themselves; no longer would a diagnosis of dementia only be disclosed to the family member and not to the person with the condition; and no longer would the diagnosis of dementia assign the person to a new social grouping characterised by marginalisation, isolation and oppression. The social construction of dementia would no longer be shaped by fear, stigma and negativity.

Pursuing a social model approach would bring a shift away from deficit-based thinking in terms of public discourse and policy for people with dementia, which frequently views them as somewhat less human and less deserving of respect. With low expectations of people with dementia, the policy approach is generally a move to protect them and guard their interests; in

doing so, this often creates more oppressive structures and cultures.

Probably where this is clearest, in public policy terms, is through inappropriate and, sometimes, premature institutionalisation of people with dementia into residential care. People are consigned to institutions which can undermine their agency and may expose them to abuse.

Behind closed institutional doors, people become detached from their communities and natural supports, their voices become difficult to hear and they are rendered passively dependent.

Article 19 of the CRPD offers an opportunity for a shift away from the focus on institutionalisation as it enshrines the rights of people with disabilities to live in the community, as well as promoting personalised services, together creating a pathway of support that suits the person. In policy terms, the social model (and the CRPD) argue for increased focus on community-based solutions to support people with dementia. Only when absolutely necessary, and when properly resourced, community-based solutions have been exhausted, should long-term residential care be used, and it must be delivered in a way that maintains a continued focus on the person's right to autonomy and dignity.

Moving dementia closer to the social model of disability and the associated principles would support advocates to challenge a lack of



investment in services and support for people with dementia. People with dementia could advocate for their rights to have appropriate levels of investment in what they need to continue to live their lives as active citizens. A social model approach argues that people with dementia must be viewed as a legitimate part of mainstream society, living in communities as equal citizens with their value recognised and respected. However, principles of non-discrimination and equality before the law present further challenges of ensuring that policy and practice are tailored for different groups of people living with dementia who experience additional disadvantage or marginalisation for reasons such as other disabilities, ethnicity or age (see box on page 18 for an example).

However, to date, none of the UK nations have explicitly framed dementia as a

disability in national dementia policies or strategies. Scotland has incorporated the HRBA and PANEL principles into its national dementia strategies, as well as practice guidance, standards for care and other relevant documents, so this creates a clear connection with the CRPD and social model of disability. The most recent policy statement on dementia in England refers to the human rights of people with dementia, but does this in relation to the human rights of older people only. It makes no mention of the CRPD, indicating a significant lack of awareness and understanding of the age prevalence of dementia or the framing of dementia as a disability and/or rights issue (Department of Health, 2015). The newly elected UK Government's position on the Human Rights Act is also the cause of some concern because of the potential implications this has for an HRBA approach towards dementia policy.

### **How the social model of disability could apply in practice: people with early onset dementia (people under the age of 65)**

Moving towards viewing dementia from the social model of disability perspective starts to break down the artificial barriers, in relation to chronological age, as qualifying criteria to access dementia services. There is a dearth in services for people under 65.

Dementia as disability enables the reframing of dementia to not just be seen as an exclusive and inevitable condition of 'old age' (with the implicit ageist sentiment that this contains). People with dementia have a right to appropriate services irrespective of age, and using the 'dementia as disability' framework would generate a much more robust debate on younger onset dementia.

The social/rights-based model can begin to influence how they are engaged and responded to in terms of services and supports. Many of the dementia activism leaders are younger people with dementia and they have often been the leading voices in the reframing of dementia as a social justice and a rights issue.

## 7. Implications for the lived experience



The shift towards the social/rights-based model also means that there is a significant opportunity for people with dementia (together with or supported by families, friends and practitioners) to act as a catalyst for change and to alter the lived experience. It requires major change in the power dynamics and stakeholder relationships. One of the most effective ways in which people with dementia can transform their lives is to have their voice heard – individually and collectively.

### 7.1 Elevating voice

Finding a collective voice can really be a powerful tool for change. The importance of the authentic voice of the lived experience cannot be denied. As the collective voice grows, the ability to become agents of change is realised. There are a number of examples of the power of the collective voice of people with dementia, including the well-established entities such as the Scottish Dementia Working Group (SDWG), the Dementia Engagement and Empowerment Project (the DEEP network), the more fledgling Irish Dementia Working Group and, at the EU level, the European Working Group supported by Alzheimer Europe. This is the social model and human rights in action.

There are an increasing number of people with dementia taking on leadership roles and engaging in dementia activism at national and global levels, often supported by or in collaboration with family carers.

People with dementia as a collective are having their voice heard and are increasingly becoming part of the dementia discourse. This replicates how people with disabilities began the process of change in relation to the social model of disability: by building a critical mass of leaders from within their own community and building collective momentum in terms of disability activism. A key element of their success was educating themselves and building their own capacity to engage in activism. Some disability activists are looking to forge alliances with carer-led groups over common issues – given the important voice that carers for some people with dementia have had, there are significant opportunities for dementia activists to work in collaboration with carers. Dementia activism presents opportunities to explore and interpret the meaning of human rights with people living with dementia in their everyday lives.



## 7.2 Language

The social model of disability also forces a rethink of the language used to describe dementia. Language is critical as it is one of the ways in which barriers are created in communities and exclusion and oppression are maintained. How many times is dementia referred to as a 'ticking time bomb', a 'global epidemic', a 'tsunami'? At the individual level, the person with dementia continues to be

framed as 'the sufferer' or the 'demented patient', with dementia referenced as a 'living death' or 'the long goodbye'. Language is an area of dementia discourse that has been addressed by a number of rights-based projects. For example, DEEP has produced a comprehensive set of best practice language guidelines, and the National Dementia Action Alliance in England declared a Call to Action on use of language and dementia in 2015.<sup>14</sup>

14. <http://dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Language.pdf>  
<http://www.dementiaaction.org.uk/dementiawords>

## 8. Implications for practice



One of the major challenges for the world of dementia is how to move towards a social/rights-based model of dementia in practice. The case study on Dementia-Friendly Communities (DFCs) outlined opposite serves to illustrate how communities, towns and cities are taking a range of steps to implement the social model largely driven by dementia activism and third sector organisations.



## **Case study: social/rights-based model in practice – Dementia-Friendly Communities**

The social model is the perfect frame for the current drive towards developing DFCs. DFCs are a manifestation of the social model of disability in practice. They are not about changing the person and getting them to 'fit in' but are, instead, about altering the social, attitudinal, architectural, and physical environments in which people with dementia live to be responsive and adapt to situations. DFCs focus on inclusion and the coming together of communities to challenge the current status quo, often characterised by the exclusions and marginalisation of people with dementia, and the reinforcement of social isolation and ongoing inequalities.

There are several DFC projects across England, Scotland, Northern Ireland, the Republic of Ireland, and elsewhere in Europe that illustrate the level of diversity and innovation that exists in communities, towns and cities. In addition, a number of organisations have produced DFC resources, toolkits and 'how-to' guides based on their experience of working with and developing DFCs. There is now a large body of experience and expertise all with the same goal: the inclusion of people with dementia in mainstream, everyday life to enhance people with dementia's lives.

There are now dementia-friendly (DF) cities (e.g. York), DF towns (e.g. Motherwell), DF tourism and leisure initiatives (e.g. Bournemouth), many examples of DF services (e.g. dentists, shops, GPs, sports and leisure clubs and art galleries), DF corporate initiatives (e.g. Lloyds Bank), dementia friends (e.g. England and Scotland), DF educational initiatives in schools, and DF environmental projects.

However, it is critical that DFCs are not just 'goodwill initiatives' operated by a variety of charitable/church-based/business type organisations. They cannot be based on benevolence but, instead, have to be embedded as rights-based initiatives that are actively supported by the relevant disability/equality legislation. The state, service providers, communities, and other delivery 'agents' of DFCs must be held to account to make sure they comply with the law at a minimum, and must promote progressive rights-based practice at their best.

The momentum that is there now for DFCs has to be embedded in mainstream laws, policies, services and practice, and this requires statutory, third sector and 'for-profit' drivers of change at a local, regional and national level.

## 9. Implications for organisations and stakeholders



There are many ways in which reframing dementia as disability would impact on organisations and stakeholders.

The disability legislation and rights-based approaches in disability/dementia are central to influencing policymakers, funders, political decision makers, businesses, health and social care providers, public services (police, first responders and emergency services), third sector organisations, disability groups, and mainstream community organisations (sporting, cultural and artistic). A move towards the social model approach requires a change in how organisations and stakeholders across the spectrum operate and respond to people with dementia. Changes in organisational strategy, leadership, organisational culture and staff education are needed. Organisations and individuals need to be supported and need to build their own capacity to facilitate these changes.

An HRBA can drive change in how dementia and mainstream services are designed and delivered. It can reframe how dementia is communicated about and described in the public arena. It would also alter how organisations fundraise, with people with dementia as the key beneficiaries of the funding. An HRBA would significantly influence the dementia research priorities and how advocacy messages are formulated. It would reformulate the nature and type of engagement with policymakers and politicians. There is a large range of organisations (at the micro level) and stakeholders in the field of dementia, including public and

private service providers, third sector organisations (including Alzheimer associations), clinicians, other health and social care practitioners, funders, researchers and academics – all of whom could utilise an HRBA in their everyday work and, in so doing, could implement a rights-based approach. Table 5 sets out the main questions that organisations and stakeholders may use to reflect on their practice in terms of using an HRBA.

As discussed, the social model of disability also opens up possibilities and opportunities for people with dementia to take a distinct view of their world and elevate their voices at the centre. Stakeholders in this scenario play a different role by providing support and leadership in solidarity with people with dementia. This then alters the current relationships, vested interests, power dynamics and the locus of control. Third sector dementia organisations, including Alzheimer associations, are ideally placed to play this role and can provide the blueprints for change across the range of stakeholders. Kate Swaffer (2014:714), a person living with younger onset dementia, writes: “If people with dementia only get ‘used’ for fundraising, or marketing or media opportunities, little will change. This type of ‘inclusion’ is tokenistic and patronizing. The worth of any sector or agency (e.g. universities, Alzheimer’s societies, service providers or community) purporting to support this marginalized and stigmatized group, and the value of the research or projects being done about them without them, is flawed without the full inclusion of, and the authentic voice of people with dementia”.



**Table 5: Key questions for organisations and stakeholders to apply the HRBA (micro level)**

<b>Social model keywords/phrases (from Table 1)</b>	<b>Questions to be addressed</b>
<b>Environmental changes</b>	<ul style="list-style-type: none"> <li>• Are physical barriers (e.g. signage, seating, pathfinding) to inclusion and participation being addressed?</li> </ul>
<b>Person at the centre of decision-making process and engagement</b>	<ul style="list-style-type: none"> <li>• Is the person with dementia involved in the decisions that affect his/her life?</li> <li>• Is the language used accessible? Is the organisation's information accessible?</li> <li>• Are dementia-friendly methods of communication used (plain English, communications tools)?</li> <li>• Is adequate time given to the person?</li> <li>• Is there an advocate available to support the person?</li> </ul>
<b>Self-determination</b>	<ul style="list-style-type: none"> <li>• Are one-to-one peer support/education activities and interventions available for people with dementia?</li> <li>• Are there opportunities to have their collective voice heard?</li> <li>• Are people with dementia portrayed positively and can they participate fully in communities?</li> </ul>
<b>Dignity and respect</b>	<ul style="list-style-type: none"> <li>• Are negative and stigmatising views of dementia challenged?</li> </ul>
<b>Active citizenship, inclusion, power and control</b>	<ul style="list-style-type: none"> <li>• Are people with dementia involved in organisational structures?</li> <li>• Is the service (health/social care/mainstream) applying the PANEL principles?</li> <li>• Is dementia awareness/education provided for personnel in the organisation?</li> <li>• Is there an organisational commitment to including people with dementia in its strategic plan?</li> <li>• Do the organisation's policies, procedures and work programmes reflect the strategic commitment?</li> <li>• Are organisational policies, procedures and practice compliant with relevant legislation, including human rights?</li> <li>• Are people with dementia and those who support them aware of their legal rights and entitlements?</li> </ul>

## 10. Viewing dementia as disability: some considerations on the debate



As the debate begins to open up about whether or not it is useful to view dementia as disability, some of the possible negative consequences and challenges need to be highlighted. It should not just be assumed that viewing dementia as a disability is universally accepted and wholly positive.

It is acknowledged that the paradigm shift in dementia towards a social/rights-based model of disability would require large-scale societal and cultural changes at both micro and macro levels that must be sustained, valued and nurtured. The extent and type of change that is needed to positively impact on the lived experience is a real challenge, as is how to move on from the existing status quo.

The change requires several 'change agents', with people with dementia being one of them. However, recent research indicates that many people with dementia have the view that it is their dementia (i.e. the condition) that is the cause of their withdrawal from and disengagement in community life and not the 'disabling barriers' that exist in these communities (Innovations in Dementia, 2011).<sup>15</sup> Many people in the earlier stages of dementia may not experience them as disabling in the way that legislation, such as the Equality Act, defines disability.

Universally accepted and agreed principles and the social model are the cornerstones of the success of the disability rights movement. While there is certainly an emerging social/rights model dialogue in dementia activism, there is still a gap in terms of an explicit set of agreed principles and model(s) which it aims to promote. Dementia activism, while still in its infancy, has already adopted the tagline: 'nothing about us, without us'. This same tagline was also used by the disability rights movement and is a very strong indication that people with dementia want to be active agents in their own lives, be self-determining, have choices, make decisions and have control over their lives. Dementia activism needs time to grow and strengthen organically and it must be supported by other willing stakeholders. Vested interests are strong and need to be challenged to change their practice. Raising awareness among and educating people with dementia and the other stakeholders is critical. Stakeholders also need to embrace a new way of working, take on different leadership roles and commit time, resources and energy to actively support people with dementia to engage in activism.

The manifestation of the lived experience for those who have embraced a disability rights approach is not a blanket approach accepted by all people with disabilities.

15. Innovation in Dementia (2011) Dementia Capable Communities: The views of people with dementia and their supporters [http://www.innovationsindementia.org.uk/DementiaCapableCommunities\\_fullreportFeb2011.pdf](http://www.innovationsindementia.org.uk/DementiaCapableCommunities_fullreportFeb2011.pdf).



Equally, people with dementia are not a homogenous group and there are those who may not wish to embrace rights-based principles in their everyday lives, as is the case in mainstream life. However, what the social model of disability does is opens up the choices and options, and offers alternatives to the current responses and approaches.

Dementia is already considered to be highly stigmatised and, if the label of disability is given, some may argue that people living with dementia will experience the additional stigma of having a disability. (Dementia is already associated with the inevitability of ageing and ageism.) It is therefore important to acknowledge the subjective experience and whether or not people with dementia see themselves as having an impairment and experience disability as a result of disabling barriers.

Equally important is the need to distinguish between this self-definition of disability and the one defined and used in law and how it includes people with dementia.

Critics of the social model/rights-based approach may take the view that the social model of disability only applies to the early stages of dementia. However, the social/rights-based model applies across the whole journey of dementia. It could be argued that there is an inverse relationship. The further one travels on the dementia journey the more relevant and meaningful is the social model, as it addresses the increasing risks of marginalisation, isolation and oppression as well as the increasing likelihood of experiencing systemic inequalities, abuse and institutionalisation.

## 11. Concluding remarks



Dementia as disability is a recent and exciting debate to emerge on the policy landscape. This paper sets out to explore some of the key issues that will help to further inform that debate and its direction.

While it is still in its early stages and will take some time to develop, there are clear indications from the narrative of people with dementia and elsewhere that it is the direction in which dementia activism is moving.

As pointed out at the outset, the notion of applying disability rights principles to dementia policy and practice is very new to many of the stakeholders, including people with dementia. What is needed now is a more rigorous analysis, research and stakeholder participation and engagement on the issue. This process needs greater and ongoing articulation of the lived experience of dementia. It must also acknowledge the dynamic nature of living with dementia.

This paper acknowledges that moving towards viewing dementia as disability is a process of transformative change. It also argues that it is not the intention that people with dementia are ascribed another negative label or social grouping by applying the social model of disability.

Instead, it is about identifying the common ground and how the social model of disability can be used to reframe and reconstruct the world of dementia. It argues that this can be done by using the social model/disability rights frameworks as well as by identifying the role human rights and disability-related legislation plays to ensure that the rights of people with dementia are upheld. The paper offers a debate on the possible implications and the impact of this reframing.

While the 'jury is still out' in terms of framing dementia as disability, there may be a certain inevitability, as many people with dementia themselves have taken ownership of the social model and it now forms part of their individual and collective identity. However, it also sets out a huge range of challenges and issues to be addressed by all stakeholders at every level. Professor Gerard Quinn, human rights lawyer and one of the architects of the CRPD said: "It seems to be that the history of human rights is really a history of gradually admitting all of humanity, group by group, into its fold."<sup>16</sup> Perhaps now there is an opportunity, through the social model of disability, for people with dementia to be welcomed into the fold.

16. Quinn, G. (2013) <http://alzheimer.ie/Alzheimer/media/SiteMedia/ImageSlider/Fixed/HR-and-Old-Age-GQfinalX.docx>.

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## **Dementia friendly communities**

There are many examples of dementia friendly communities across the UK. These references and links are only a small selection suggested by people who commented on this report.

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## **National and international legislation**

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# Appendix A



## 26 March 2015 Roundtable Event

### **Rights, dementia and the social model of disability: A new direction for policy and practice?**

The Abbey Centre – Parker Morris Hall, 34 Great Smith Street, London SW1P 3BU

### **Event programme**

<b>10.15</b>	Arrive – refreshments
<b>10.45</b>	Chair’s welcome – aims of the day (Toby Williamson – Mental Health Foundation)
<b>11.00</b>	Jenny Edwards CBE – Chief Executive, Mental Health Foundation
<b>11.10</b>	Keith Oliver – a personal perspective
<b>11.20</b>	Rights, dementia and the social model of disability – a Mental Health Foundation policy discussion paper (Gráinne McGettrick)
<b>11.45</b>	Break
<b>11.50</b>	Jayne Goodrick – a personal perspective
<b>12.00</b>	What can disability activism achieve? (John Evans – Equality in Living)
<b>12.25</b>	Roundtable discussions – how is it helpful to consider dementia from a rights-based perspective and using the social model of disability?
<b>12.55</b>	Feedback from discussions
<b>1.00</b>	Lunch
<b>1.45</b>	Peter Ashley – a personal perspective
<b>1.55</b>	Using a rights-based approach to support people with dementia – examples from the Alzheimer’s Society (Sam Cox)
<b>2.15</b>	Roundtable discussions – what needs to happen next? What actions can you take away from today?
<b>3.00</b>	Break
<b>3.15</b>	Feedback from discussions
<b>3.50</b>	Chair’s summing up and next steps
<b>4.00</b>	Close

## Appendix B



### Summary Notes from roundtable discussions and areas for action

26 March 2015

**Participants at the event were asked to consider two questions in their roundtable discussions. The bullet points summarise the main responses.**

#### **Session 1: How is it helpful to consider dementia from a rights-based perspective and using the social model of disability?**

- It's taken a long time for dementia organisations (including charities) and practitioners to begin to challenge the dominant medical model – but the wider disability activist movement has not been very effective at involving people with mental health problems and conditions, especially dementia. Even this paper defines dementia in terms of the medical model. Barriers to using this perspective/model for people with dementia may partly have been because of low rates of diagnosis, late diagnosis, older people being less involved in activism of this nature, dominance of carers' voice, the effect of dementia on a person's cognition, communication, and decision making, framing dementia only as an issue of old age rather than disability (as in the 'Prime Minister challenge on dementia for 2020'), benefits accrued (e.g. by charities), or portraying people with dementia as 'victims' within a medical model. Dementia can be seen to pose unique challenges for it being understood as a disability, so awareness raising and education is needed to achieve this.
- It needs acknowledging that disability activists had a long struggle (and it's still ongoing in some respects) to achieve accessibility, inclusion, equal rights as citizens – this was partly achieved through community and collective action, and visible political action, not just individuals taking action alone. Yet, the increased visibility and inclusion of, e.g., people in wheelchairs, shows how much could be achieved and that the HRBA (human rights-based approach) and SMD (social model of disability) provide a framework for understanding, coming together, and expressing the need for change.
- Important to acknowledge that dementia is a disability in terms of the SMD, and relevance of a HRBA to policy, service and practice development. This may be challenging for many people working in health and social care (as well as people with dementia and carers) – so, the policy paper is about raising awareness (and expectations) among people with dementia, carers, practitioners, and the general public. SMD hasn't had much traction in



healthcare and needs to gain more traction in social care (which still focuses on issues of personal support, service provision, 'independent' living, rather than people's lives in communities, citizenship, 'interdependent' living, etc. – but, maybe the wellbeing principle in the Care Act 2014 provides an opportunity to shift this a little).

- Important to flag up issues for people with co-morbidities – e.g. people with learning disabilities and dementia, physical/sensory impairments and dementia, and mustn't lose sight of people with very severe dementia – but also acknowledge age, gender, ethnicity etc. as potential sources of additional discrimination (e.g. early onset dementia).
- It was queried if there should be a focus on dementia at all because of this being a diagnostic-led approach. Yet, dementia stands out as being left behind in disability activism – people often aren't aware of their right to health and social care services, employment support, housing, disability benefits (including the need for advocacy to obtain these), let alone the human rights and the SMD. Foucault's 'panopticon' was invoked as a metaphor for the role of statutory services, as opposed to being active 'duty holders' responsible for raising awareness, promoting and ensuring the application of human rights for people with disabilities.
- Support for people with disabilities (e.g. welfare benefits/employment support) is not designed taking into account people with dementia (e.g. to help people with early onset dementia to retain employment), so this is not just about health and social care services. Community support that is available can cause further problems because independent living may result in people becoming excluded and lonely.

## **Session 2: What needs to happen next to apply a rights-based approach and the social model of disability in the field of dementia? What actions can you take away from today?**

- There needs to be greater awareness, understanding and application of HRBA and PANEL principles in policy and practice development more widely in general, including the general public, not just in dementia or health and social care. The mainstream media has a role to play. To exercise their rights, it is also vital that individuals (with dementia and their carers) know about their rights. This requires significant information and education, as well as changes in attitudes and behaviour, and there will be opposition. But, additional benefits of HRBA and PANEL are that they pick up other aspects of discrimination that may affect people with dementia not just disability, e.g. age, gender, ethnicity, etc.
- Rights don't need to be framed only in legal terms – moral rights have value as well, and can sometimes be more effective at changing hearts and minds. 'Soft' rights, such as those expressed by Kitwood, may be effective to initially engage and raise awareness among people and practitioners (especially if links are made with professional ethics, etc.



through training and education). But using both the carrot and the stick, as appropriate, may be the best approach.

- There are significant variations of awareness across the UK – e.g. Scotland has an explicit HRBA in its development and implementation of national dementia policy. Further devolution may provide more opportunities.
- The role of people living with dementia, and networks such as the Dementia Engagement and Empowerment Project (DEEP), etc., in challenging dominant narratives about dementia (e.g. the medical model description) and providing a ‘push’ in the direction of HRBA is vital. Human ‘agency’ is important, i.e. respecting the right of people to make decisions about the action they wish to take, and there may be different responses and views expressed which should also be respected. But, people will often need support to do this at an individual level (e.g. personal assistants – still quite rare compared to other disability groups). This includes the role of families and friends (as carers and supporters) – working together with people with dementia to secure their rights jointly.
- Building an evidence base and narratives for dementia as a disability is important – disability activists have included prominent writers and academics.
- Make links with the ‘assets-based’ approach as well, which focus on people’s strengths and what they can do, not what they can’t – this should not exclude people with more severe dementia.

### **Areas for action:**

1. Raising awareness about rights, HRBA and SMD in dementia through Dementia Action Alliances, dementia friendly community initiatives, etc.
2. Organisations explicitly applying (and being evaluated/audited against) an HRBA and PANEL principles in:
  - a. national and local dementia policy/strategy development;
  - b. dementia service development and commissioning activities;
  - c. professional education and training for dementia;
  - d. age-friendly cities and integration initiatives.
3. Incorporating a focus on rights, citizenship and inclusion into the care pathways of people with dementia.
4. Organisations systematically recording breaches of human rights and challenging where possible – e.g. taking test cases under the Equality Act, employment laws, etc.



5. Mainstream disability, social care, and human rights organisations actively developing workstreams and workstream leads on a 'rights and disability agenda' which can support activities in 2, above.
6. Disability studies organisations (e.g. universities) undertaking projects to develop understanding and evidence around the HRBA and SMD in relation to dementia.
7. Dementia organisations actively engaging and promoting dementia to the United Nations Committee responsible for the CRPD, and the UK Government and others involved in reporting UK compliance with the United Nations CRPD in 2016. This must include providing support for people with dementia to play an active role in this process.

## Appendix C



### Kitwood's malignant social psychology and Kitwood's 'flower'

**Tom Kitwood identified a number of behaviours and practices that were profoundly negative and abusive towards a person with dementia. He used the term "malignant social psychology" to describe this, and they include:**

- Treachery
- Disempowerment
- Infantilisation
- Intimidation
- Labelling
- Stigmatisation
- Outpacing
- Invalidation
- Banishment
- Objectification
- Ignoring
- Imposition
- Withholding
- Accusation
- Disruption
- Disparagement
- Mockery

To describe the key elements of respecting personhood and ensuring the wellbeing of a person with dementia, Kitwood used the symbol of a flower:







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