



Mental Health  
Foundation

# Dementia, rights and the social model of disability

A new direction for policy and practice?

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## Key Messages

- There is currently a move toward using a rights-based approach and the social-model of disability to replace the more traditional medicalised approach towards dementia.
- The social model of disability will provide greater autonomy, dignity and influence to people with dementia.
- Legislation has a major role in driving the institutional and systemic changes needed.
- With cross-sector support and mechanisms for accountability a rights-based approach and the social model of disability can play a central role in the creation of Dementia Friendly Communities.
- This paradigm shift must take into account certain considerations, including: the views of those with dementia, the co-ordination of stakeholders, collective promotion of a rights-based approach and the social model of disability in relation to dementia, and consensus around the extent and type of systemic and societal changes.

**Dementia is an umbrella term for a range of conditions that cause damage to the brain. These conditions impact a person's memory, thinking, language and ability to carry out everyday tasks. There are currently 850,000 people with dementia in the UK<sup>1</sup>. Despite the resulting impairments, dementia is not readily recognised as a disability in policy and practice terms and therefore is not at the forefront of human rights debates in the same way as other issues and groups in society.**

'Disability' refers to the physical, psychological and cognitive impairments that arise from illnesses, diseases and health conditions. The rights enshrined in national and international human rights law and conventions ensure that people with these impairments are not excluded or treated unfairly, and can be accommodated in the same way as non-disabled people.

Therefore, the use of 'disability' is 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.

People with dementia have a range of impairments and as a result face several disabling barriers including attitudinal, social, psychological, physical and institutional ones.

Dementia discourse has historically been dominated by a highly 'medicalised' notion of dementia. However, there has been a recent shift toward dementia being viewed as having a rights-based dimension.

## The Current Legal Environment

People with dementia have the same civil and legal rights as everyone else as the Human Rights Act 1998 and the European Convention on Human Rights apply to everyone.

Here are how some current laws are relevant to people with dementia in realising their human rights:

### *Equality legislation*

The Equality Act 2010 does not have an extensive list of every disability covered - instead it defines a disability as 'a physical or mental impairment' that has a 'substantial and long-term adverse effect' on carrying out normal activities.

People with mid to late stage dementia clearly fall within the scope of the Act. Full protection includes 'reasonable' adjustments' by employers - or to ensure that, as far as is reasonable, a disabled worker or customer has the same access to everything that is involved in doing and keeping a job or using a service as a non-disabled person - as well as freedom from discrimination.

There is an argument that people with early onset dementia should decide for themselves when they become 'disabled' by their dementia.

### *Mental capacity legislation*

Mental capacity legislation aims to provide greater autonomy for individuals facing cognitive impairments by supporting them to make decisions for themselves wherever possible.

Unfortunately, its use has been found to overly protective, risk adverse cultures in health and social care that undermine autonomous decision making and self-determination.

### *Human rights*

The Human Rights Act 1998 (HRA)

provides the UK with a legislative framework to implement the European Convention on the Human Rights (ECHR), which apply to everyone. 5 ECHR rights are very applicable to supporting people with dementia:

- **Article 2** – the right to life
- **Article 3** – prohibits inhuman or degrading treatment or punishment
- **Article 5** – everyone has the right to liberty and security of person
- **Article 8** – the right to private and family life
- **Article 14** – freedom from discrimination, including on the grounds of disability

Laws and policies by the government and public bodies can be taken to the European Court if they violate a person's human rights.

### *Social care legislation*

The Care Act 2014 brings social care and local authority responsibilities into a single piece of legislation. Public bodies are now obliged to uphold and focus on individual wellbeing, its overarching principle.

### *The United Nations Convention on the Rights of Persons with Disabilities (CRPD)*

The CRPD sets out the legal framework for human rights legislation in relation to people with disabilities (including cognitive impairments) and makes direct reference to the social model of disability – namely that barriers to participation in society contribute towards 'disability'.

The United Kingdom has ratified the CRPD, which means national laws and government policies should be compliant with it.

**Human rights legislation and other laws that affect people with disabilities also apply to people with dementia. Some of these laws are based upon the social model of disability.**

## **The Social Model of Disability**

The 'medical model of disability' was used by the disability rights movement to explain disabled people's exclusion from mainstream social and economic life, their oppression and their lack of recognition as having basic human rights.

The social model of disability has since emerged as the disability rights movements' response to the medical model and embodies what disabled people want their lives to be – empowered with rights and the ability to live a life of their own choosing. The Equality Act and CRPD are based upon the social model of disability.

A more radical social model of disability was initially adopted that required changes in broad environmental factors, viewing these as the cause of people's disability, rather than trying to change the disability itself<sup>2</sup>. This evolved in the 1990s into a variation that proposed greater credence to the personal experience of having a disability, in conjunction with their political and social context<sup>3</sup>.

The benefits and practical changes of adopting the social model for dementia would include:

- A more person-centred, autonomous and community-based system which sees dementia as an issue of rights, social justice and equality
- Greater rights for accessing services in social care
- A focus on living in the community, with personalised services
- When in residential care, a greater focus on the right to autonomy and dignity

## **Applying the Social Model**

At the core of the social model of disability is a human rights perspective. The 'Human Rights Based Approach' (HRBA)<sup>3</sup> is a tool that has been developed

to allow practitioners, service providers or policy makers to examine whether they are putting human rights into practice. Five 'PANEL principles' have been developed:

*Participation* – Are people with dementia included in the process of policy making? Have their barriers to involvement been identified and addressed?

*Accountability* – Who is responsible for ensuring responsibilities have been carried out? What is the mechanism for ensuring accountability?

*Non-discrimination and equality* – When making decisions, ensure the human rights of people with dementia have been considered and upheld.

*Empowerment* – Ensure people with dementia understand their rights and are supported in participating in the development of policies and practices which affect their lives.

*Legality of rights* – Follow national and international law that requires the human rights of people with dementia to be incorporated into all government policy.

HRBA and the PANEL principles have real potential to offer a practical tool in policy development for people with dementia as well as for practice and service development. Scotland has already introduced the PANEL principles into its national dementia strategies, practice guidance and standards of care<sup>4</sup>.

## **Implications**

### *Implications for policy discourse and service provision*

Viewing dementia from the social model provides an alternative framework to rethink and re-imagine dementia as a rights, social justice and equality

issue, which opens up the policy focus beyond the narrow health and social care framework.

This shift has the potential for policy to be developed and services designed, delivered and monitored by people living with dementia, who will have a strengthened ability to advocate for appropriate levels of investment in social care so they can live as active citizens in the community.

The biggest potential opportunity in relation to public policy would be a shift away from inappropriate and sometimes premature institutionalisation towards community-based support.

### *Implications for the lived experience*

There is a significant opportunity for people with dementia to act as a catalyst for change and to alter their lived experience. It requires major change in the power dynamics and stakeholder relationships.

Finding a collective voice is one of the most effective ways for people with dementia to change their lives and this can already be seen by the increasing number of people with dementia in leadership roles and engaging in dementia activism at a local and national level.

The social model will also force a rethink of the language used when talking about dementia. This is already underway, with the Dementia Engagement & Empowerment Project (DEEP) having produced a comprehensive set of best practice language guidelines<sup>5</sup>.

### *Implications for practice*

Implementation of the social model will be largely driven by dementia activists and third sector organisations. For instance, creating dementia friendly communities (DFCs) is already seeing changes to cities, towns, tourism and

leisure initiatives, services, corporate initiatives as well as educational initiatives and environmental projects and a rights based approach and the social model can support and enhance this. In practice, these changes will require:

- Raising awareness and understanding of legalisation and the social model in developing DFCs across all stakeholders
- The government to hold service providers, public bodies, communities and organisations to account and monitor adherence to rights-based approaches in dementia friendly practices.

*Implications for organisations and stakeholders*

Reframing dementia with a rights-based approach to disability will require all organisations and stakeholders to make changes in the way business is conducted. Organisations must be supported in this change and will be encouraged to follow a social model using the Human Rights Based Approach (HRBA) when designing and delivery services (see above). Key implications include:

- The way dementia is communicated and described
- The way organisations fundraise alongside people with dementia
- The nature and type of engagement with policy makers and politicians about dementia
- The formulation of policy messages and dementia research priorities

### **Challenges and Considerations**

- There is no consensus about the extent and type of changes required for large scale societal and cultural changes.
- Recent research suggests that most people with dementia still follow the traditional medicalised view of dementia – namely that it is their condition (dementia) which is the cause of community disengagement, rather than disabling barriers from the outside.
- There remains a gap in terms of an explicit set of agreed principles that the dementia activists will aim to promote. Stakeholders need to better co-ordinate their efforts in this movement of social and cultural change.
- Not everyone with dementia will see themselves as having a disability or wish to embrace the rights-based principles to disability. It is important to explain the difference between a self-definition of disability and one used by law, and not to view people with dementia as a homogenous group.

### **Next Steps**

Applying disability rights principles to dementia policy and practice is a new concept that requires:

1. More rigorous analysis and research
2. Stakeholder participation and engagement, with a particular focus on gathering views from people with dementia
3. On-going articulation and research into the lived experience of dementia and the dynamic nature of the condition
4. Raising awareness and understanding of a human rights based approach and considering opportunities to apply it in policy and practice affecting people with dementia

## References

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The Mental Health Foundation, incorporating the Foundation for People with Learning Disabilities (FPLD), is the leading UK charity working in the field of mental health and learning disability.

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*The Mental Health Foundation, a UK wide charity, has been in existence for 65 years. We focus on researching and evaluating fresh approaches to mental health with a view to advocating helpful policy change and the roll out of best practice more widely.*

*Our work is centred on prevention – we believe that there is far more scope for interventions that prevent people developing mental health problems and which sustain recovery.*

*Access to mental health services is critical, but as a society we also need to focus on bringing down the need for these services and developing good mental health for all.*

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