



Mental Health
Foundation

KEY POINTS



Dementia, rights, and the social model of disability

A new direction for policy and practice?

What is This Paper About?



This paper is about a different way of looking at dementia.

Most people still see dementia as an individual's problem.

They might say: "YOU have dementia, so that's why you can't understand the bus timetable."

Other people see that bad environments and the attitudes of others can also be a major barrier to people with dementia.

They might say: "The bus timetable is badly written and designed – it's hard for **everyone** to read."

There isn't much that we can do about dementia at the moment. But, there is a lot we can do about the environment and the experiences that people have.

So, it's not surprising that some people with dementia, and their supporters, are starting to talk about **Rights**.

For example, the **Right** to have information presented clearly in a way that is easy to understand for everyone, including people with dementia.

We think that more people should be involved in this discussion. This report has been written to help this discussion.

This is a key points summary. The full version of the paper can be found at www.mentalhealth.org.uk/publications

Dementia, Disability and Rights



Thinking about the **Rights** of people with dementia is quite new.

But, the idea of rights for disabled people has been around for a long time. People with physical disabilities fought a long battle for anti-discrimination laws to protect disabled people.

When the law talks about “disability” it is referring to the various impairments caused by illnesses and conditions; it talks about how people should be protected from unfair treatment because of their impairments.

Many people with dementia would be classed as ‘disabled’ under law.

‘Disability rights’, as they are called, have made a huge impact on the lives of disabled people.

This includes laws, like the Equality Act, which have led to massive improvements in the physical environment, transport, education and employment for people with physical disabilities.

So, while many people with dementia would have rights under the law, the question is: why have so few people used them?

National and International Laws



This section looks at laws that might give rights to people with dementia.

The Equality Act 2010

This is the law that protects disabled people from unfair discrimination in the UK.

It 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.”

So, clearly many people with dementia would be classed as ‘disabled’ under this law.

Some might not though, especially those in the early stages of dementia.

The Mental Capacity Act 2005

This law is partly about people’s rights to make decisions for themselves. Mental capacity means the ability to make decisions. Sometimes, people with dementia may have difficulty making decisions. The law is also about people’s rights if they are unable to make a decision.

Some people are concerned that, in practice, it has not been properly used.



The Human Rights Act 1998

This law allowed the European Convention on Human Rights to be used in the UK. The Convention is an international treaty that protects human rights and fundamental freedoms in Europe.

The Care Act 2014

Under this law, councils have a duty to support people so they can be as involved as much as possible in decisions that affect them and their communities. It pulls together lots of existing laws about how people are supported. It talks about a person's "wellbeing", rather than just about their need for care.

It is now in force and could prove to be a very powerful way for people with dementia, and their carers, to secure their rights.

The United Nations Convention on the Rights of Persons with Disabilities 2006 (CRPD)

This is an international treaty which protects the rights of disabled people.

It recognises that people are often 'disabled' by the environment and the attitudes of others, as much as they are by their individual impairments.

This approach is known as the **Social Model of Disability**, and we will look at this in more detail below.

The UK has ratified the CRPD, which means that our laws and government policies should comply with it. **However**, this has yet to be tested and there are questions about whether many UK laws and policies actually comply.



One good example of this concerns access to 'social care'.

In the UK, we all have access to free healthcare through the NHS.

However, many of the services that people with dementia need are classed not as 'healthcare', but as 'social' care. This often means that they are not free.

In theory, at least, this could be challenged under the Convention.

In 2016, the UK has to report to the United Nations about how well our laws comply with the Convention.

What does this all mean?

What most of these laws have in common is that they all talk about disabled people and disability, rather than specific conditions like dementia.

This means that there is real value in thinking about many people with dementia as disabled people, simply because:

- it gets us thinking more from the point of view of **Rights**;
- it means we look at the environment and attitudes of others to see what can be done to make life easier and fairer for people with dementia.

The Social Model of Disability



This section looks at ways of thinking about disability that go beyond a 'medical' view.

Dementia has mostly been seen as a 'medical' issue. It sees the person and their dementia as 'the problem'.

This is known as the 'medical model'.

The same used to be applied to people with physical disabilities.

The medical model said: "You are the problem because your legs don't work."

In the 1970s, some people started to say: "Yes, but what about those steps up to the library? What about the fact that people treat me as a second-class citizen? These things are just as much of a problem as my legs not working."

This became known as the 'social model'. The argument is that people are often disabled as much by their environments and the attitudes of other people as they are by their medical conditions.

In the 1970s and 1980s, disabled people started to use the social model to challenge the way they were seen by society.

It resulted in huge changes to the way many people with disabilities saw themselves, how they were seen by others, and the experiences they had.

Laws like the Equality Act and the CRPD are based on the social model of disability.

Now, people with dementia are starting to ask the same questions.



Perhaps people with dementia are often disabled more by their environment and the attitudes of others than they are by their dementia.

Perhaps people with dementia have the right to ask whether this is fair.

The table opposite shows the different ways the medical model and the social model approach dementia:

Of course, the medical perspective is still vitally important, but many people think that we need to shift the balance.



The medical model encourages attitudes that say:	The social model says:
<p>You are the problem. It is about what you can't do. The most important thing is a cure for dementia.</p>	<p>A cure would be great of course, but meanwhile there are lots of barriers to people with dementia. These include the attitudes of others and the physical environment. Let's look at what people with dementia can do.</p>
<p>People with dementia can't make decisions.</p>	<p>People with dementia should be at the centre of the process of making decisions, wherever possible, and should be supported to participate fully.</p>
<p>People with dementia are victims or sufferers and need our sympathy.</p>	<p>People with dementia have rights, deserve respect, and are much more than their dementia.</p>
<p>People with dementia are passive dependents.</p>	<p>People with dementia can be active citizens.</p>
<p>Dementia policy and services do things to or for people with dementia.</p>	<p>Policy and services do things with people with dementia.</p>

How Might This Change Things?



How might this change the way that we think about dementia?

It is fair to say that expectations of people with dementia are low:

- among the general public
- among people who make policy and laws
- among professionals and other staff
- within organisations
- among people with dementia themselves

Using the social model to think about dementia might help us to move away from an approach to dementia that is heavily focused on what people **can't** do. This is sometimes known as 'deficit-based' thinking.

Here are some examples of what happens when deficit-based thinking dominates:

- A diagnosis of dementia is told to the family and not to the person with dementia.
- Someone gets a diagnosis and is immediately seen as 'different' from the person they were the day before.
- People speak to the carer, not the person with dementia – "Does he take sugar?"
- People with dementia are described as "sufferers", "victims" or worse.
- People with dementia are considered an acceptable target for humour and derision.
- People with dementia are not given a voice in decisions that affect them.



- People with dementia are placed into care homes, often long before they need to be.

Much of this will be very familiar to people with dementia reading this paper.

Thinking differently might mean that:

- We assume that people with dementia can and should speak for themselves; therefore, we should make every effort to support them to do so.
- People with dementia are treated as fully human and deserving of respect.
- We don't just think about dementia as all about 'care'.
- A diagnosis is no longer viewed as life-ending.
- We focus on what people **can** do rather than mainly on what they can't.
- People with dementia have a stronger sense of a right to their place in the world, rather than as grateful recipients of help.
- People with dementia develop a stronger voice in policy decisions.
- We agree that people with dementia have the right to a say in decisions that affect their lives, at all levels.

Doing things like this puts the social model of disability into practice.

And, because laws like the Equality Act and the CRPD are based on the social model of disability, it is using the law positively to benefit people with dementia.

Making sure that laws (and policies) are used in this way is a process called a 'human rights-based approach'.

In Conclusion



The voices of people with dementia have only very recently started to be heard, but the 'movement' is growing.

People with dementia, of course, have different lives, different views and different aspirations.

What many people with dementia share in common, though, is the view that they have a **right** to a say in their lives.

Perhaps changing the way we think about dementia will encourage more people to get involved in the conversation.

As Professor Gerard Quinn, a human rights lawyer, 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".

Now is the time for people with dementia to be welcomed into the fold.

Information About This Paper



This paper was written by Steve Milton at Innovations in Dementia and was produced by the Mental Health Foundation. The work was funded by the Joseph Rowntree Foundation.

Innovations in Dementia is a community interest company that works nationally with people with dementia, partner organisations and professionals. Its aim is to develop and test projects that will enhance the lives of people with dementia.

The Mental Health Foundation is a UK charity that does social research, service development and policy work on issues affecting people with mental health problems, dementia, and learning disabilities.

An expert advisory group that included people with dementia was consulted to help produce the paper.

We also held an event in London to discuss the issues covered in the paper. People with dementia participated in this event.

We changed the paper based upon comments from the expert advisory group and the London event.

We would like to thank everyone who has helped contribute to this paper.



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