



Wellbeing for Life Challenging Discrimination and Stigma



Learning Outcomes

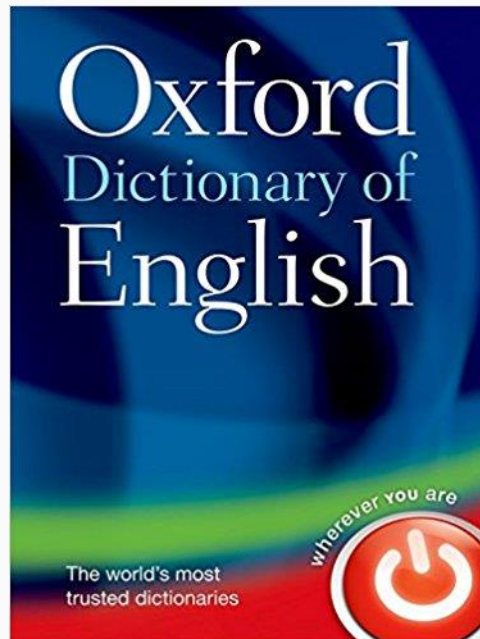
- Having an understanding of what discrimination and stigma is and how it can affect a person.
- Knowing how to recognise when a person is being discriminated against.
- Knowing who to report concerns to.



Definition of Discrimination

The Oxford English Dictionary describes discrimination as:

“The unjust or prejudicial treatment of different categories of people, especially on the grounds of race, age or sex”





Why people with a learning disability are at increased risk of discrimination

Even before a person with a learning disability develops dementia, they are likely to have been subjected to discrimination as a result of other people's attitudes towards them.

You may have seen examples of discrimination when you have supported a person in the community, or even from supporting a person to access healthcare or other services that you might take for granted in your personal life.

If a person with a learning disability then develops dementia, discrimination can be compounded through the mistaken beliefs of other people or attitudes from within communities.

People from minority groups like BAME (Black, Asian and Minority Ethnic), LGBT (Lesbian, Gay, Bisexual and Transgender) and traveller communities are amongst other sectors of society that face increased discrimination, and if a person with a learning disability also aligns themselves with one of these groups they are likely to be subjected to even greater levels of marginalisation and discrimination.



Additional Discrimination seen when People have Dementia

People with dementia may be discriminated against because it is believed that they have 'lost their mind' and are 'stupid'. Discrimination may also be related to ageism, or the belief that the person has lost capacity (when the person has capacity) or that they cannot be helped with something (like a health care issue) even when they can. All of these attitudes are wrong.

Despite awareness-raising campaigns challenging negative attitudes towards people with dementia, many people still experience discrimination on a daily basis. Discrimination can occur anywhere, including retail and other business environments, through service providers (like banks or public transport companies), from within community groups, councils or health and social care providers.



Additional Discrimination seen when People have Dementia

Discrimination often takes the form of making what would otherwise be considered regular aspects of daily life inaccessible for a person with dementia, often because the people in control of shops, services or social events are unwilling to make changes or allowances for the needs of a person with dementia.

Potentially all areas of society are capable of discriminating against people with dementia, and although discrimination is against the law, this doesn't stop people from having prejudicial attitudes or demonstrating them either overtly or covertly through the way they conduct themselves in their personal life or through their work.

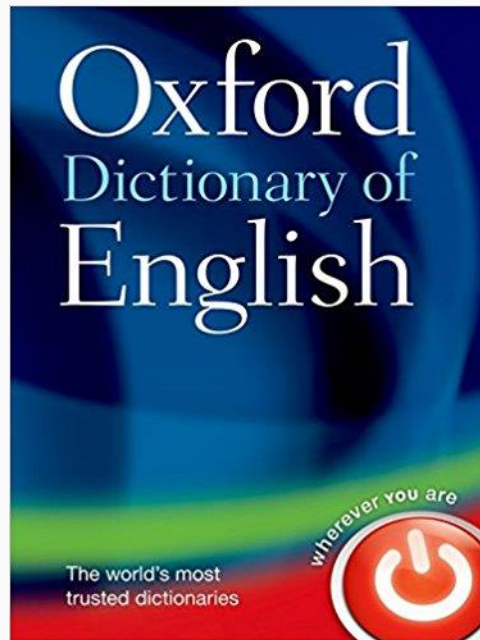
Even when discrimination is more subtle or masked in some way, it can still be deeply offensive to the person and have a detrimental effect on their quality of life and wellbeing.



Definition of Stigma

The Oxford English Dictionary describes stigma as:

“A mark of disgrace associated with a particular circumstance, quality or person”





Why Stigma is Historically a BIG Problem in Dementia

Stigma has historically been one of the biggest, if not the biggest, challenge in improving awareness, understanding and support for people with dementia.

Stigma has contributed to historically negative societal attitudes to dementia, low diagnosis rates, cruel care and support practices, and it could be argued has also resulted in poor funding for dementia research.

In its crudest form, stigma has brandished people with dementia as 'mad', 'bad' and 'dangerous' and in some cultures dementia is even associated with witchcraft. When some people think of dementia they still have visions of asylums and 'care' practices that have inflicted pain and humiliation on people with dementia.

Modern thinking is now clear that anyone who promotes stigmatising views or practices has no place in the care and support of people with dementia.



The Importance of Challenging Stigma to Support Living Well

From *‘Living well with dementia: A National Dementia Strategy’ – England’s first dementia strategy, published in 2009:*

“We need to ensure better knowledge about dementia and remove the stigma that sadly still surrounds it. The challenge of removing common misconceptions is crucial. Dementia is not a natural consequence of ageing and it is not true that nothing can be done for people with the condition. In reality, a great deal can be done to help people overcome the problems of dementia, to prevent crises and to improve the quality of life of all involved.”

“We must remove the stigma attached to dementia, which is similar in many ways to the stigma that cancer used to carry in the past.”





What has been Done to Tackle Stigma?

Many initiatives have been implemented since the 2009 Dementia Strategy to reduce stigma. Examples include:

- Dementia Friends, the national movement to improve awareness and understanding of dementia. The numbers of people becoming Dementia Friends or Dementia Friends Champions has grown year after year since Dementia Friends began in 2012.
- Many communities are considered to be 'Dementia Friendly' after changing and improving the way they support people with dementia, and the numbers of these communities continues to grow.
- Increased training for health and social care professionals in dementia care and support has helped to improve the experiences people with dementia have when accessing NHS care or the services of social care providers.

The National Ambition for Reducing Discrimination and Stigma

Prime Minister's challenge on
dementia 2020



February 2015

From the “Prime Minister’s Challenge on Dementia 2020”

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf:

“We want a society where the public thinks and feels differently about dementia, where there is less fear, stigma and discrimination; and more understanding.”



How Discrimination and Stigma can make a Person Feel

Discrimination and stigma are degrading, demoralising and go completely against the idea of living well with dementia.

They can make a person feel worthless or as though there is no point in going on. They can dramatically deskill a person if they are unable to conduct their daily life as they need to and would want to, and at their worst they can make a person feel like they have some terrible plague that other people must avoid at all costs.

Discrimination and stigma help loneliness to flourish, isolating people from their communities, and increasing the person's likelihood of more rapid deterioration with their dementia.

Recognising Discrimination and Stigma in Everyday Life

Discrimination and stigma can manifest themselves in many different ways:

Obvious examples are a person with a learning disability and dementia being refused entry to a place that they would otherwise be able to access, or being told that they will not be considered for treatment for a health condition that is otherwise treatable because they have a learning disability and dementia.



Recognising Discrimination and Stigma in Everyday Life

More common examples you might see are disapproving glances; groups/individuals staring with disgusted expressions at the person you support when they are out in the community; or derogatory comments about the person that are either made directly to them or that you cannot fail to overhear.

Remember though: There is no set pattern or formula for the ways in which discrimination and stigma proliferate.





How to Support a Person when they are the Subject of Discrimination or Stigma

It is vital that discrimination and stigma is never ignored, accepted or allowed to flourish.

Whilst you should never put yourself or the person you support in danger by challenging the discriminatory or stigmatising views or practices of other people when you encounter them in the community, if you have a genuine and safe opportunity to help people in your community to understand dementia better and reassess their viewpoints, try to seize that opportunity.

If discrimination or stigma is related to the person's access to healthcare, you should work as a team with your line manager and colleagues to help to identify ways in which the person can have the healthcare that is in their best interests.

Reporting Concerns



If you or the person you support ever feel threatened by more severe forms of discrimination or stigma – particularly when out and about in the community - you should always report this to your line manager.

If you ever find yourself in an acute situation, call the Police.

Never accept discrimination or stigma as a normal part of the life of a person with a learning disability and dementia, or as being something that just 'goes with your job'. Both of these viewpoints are wrong.



How you can avoid being Discriminatory or Stigmatising

As a health or social care professional, you would always be expected to avoid acting or speaking in any way that is discriminatory or stigmatising.

However, sometimes through a lapse in judgement or because you simply don't realise something you have said or done is discriminatory or stigmatising, you may find yourself inadvertently contributing to a person's distress.

To avoid this, it is vital to ensure you are well educated in best practice for supporting a person with a learning disability and dementia, with particular reference to your attitude towards the people you support and the language that you use in relation to dementia.

Mind your language! (And other people's)

The language that is used around dementia directly contributes to the way people think and feel about dementia and people living with dementia. As Agnes Houston, a lady living with dementia, says:



How you can avoid being Discriminatory or Stigmatising

“Words are very powerful - they can build you up or put you down. When you are speaking about dementia, remember this.”

Language guidelines have been created to demonstrate positive and negative examples of dementia language, and links to these are available in the resources document that accompanies this module.

Please familiarise yourself with these guidelines, use them when talking or writing (for example in support plans) about dementia or a person living with dementia, and signpost other people to them to help combat discriminatory and stigmatising language in dementia care and support.



Combating Discrimination and Stigma

Hopefully this module has inspired you to do your part in combating discrimination and stigma against people with a learning disability and dementia.

Ways you might be able to do this include:

- Signposting people to dementia language guidelines.
- Becoming a Dementia Friend – you can do this in a face-to-face session or online, and once you are a Dementia Friend wearing your badge can help to spark conversations when you are out and about. Be aware, however, that becoming a Dementia Friend does not give you the level of dementia training needed when you are working in health and social care. Additional and ongoing training that is appropriate for your role should always be provided by your employer.



Combating Discrimination and Stigma

- Becoming a Dementia Friends Champion and holding information sessions in your local community.
- Your service joining your local Dementia Action Alliance (if you have one) and working with them to improve your local area for people who are living with dementia.
- Your service helping your local area to work towards being a recognised 'Dementia Friendly Community'.
- Having an open day, fete, coffee morning or other event in your service that welcomes people from your local community and provides information about learning disabilities and dementia



Taking inspiration from the Disability Movement

One method for challenging discrimination and stigma that is gaining increasing interest amongst activists seeking to improve quality of life for people with dementia is through aligning dementia with disability.

The disability movement have successfully challenged discrimination and stigma in all walks of life, and this has resulted in legislation and tangible improvements to everyday life for people with disabilities. There is still a long way to go, but examples of wheelchair friendly communities are widespread and commonplace.



Taking inspiration from the Disability Movement

The fight for dementia to be seen as a disability and therefore included in the same rights and protections that exist for people with a disability continues.





Education! Education! Education!

All the progress that has been made in challenging discrimination and stigma, and all the progress that still needs to be made, hinges on educating people.

Many high profile advocates who are living with dementia themselves dedicate a huge amount of time to furthering this education agenda, and we all have a role to play.

Please read the resources document that accompanies this module, and within those links be inspired to do your bit towards reducing - and hopefully one day removing - discrimination and stigma from the lives of everyone who is living with dementia.



Produced by the MacIntyre Dementia Project with the support of an Innovation, Excellence and Strategic Development Fund Award from the Department of Health

A special thank you to Beth Britton, and for all her hard work on the MacIntyre Dementia Project.

<https://www.bethbritton.com/>

© MacIntyre 2018. All rights reserved
602 South Seventh Street
Central Milton Keynes
MK9 2JA
www.macintyrecharity.org