

THE CONVERSATION

Academic rigour, journalistic flair



VonaUA/Shutterstock

People with intellectual disabilities are often not told about their medicines and their potential side effects

August 1, 2019 2.12pm BST

The 1.5m people in the UK with an intellectual disability experience significant health inequality. Research shows that they are more likely to develop health problems than the general population, they are more likely to have reduced access to healthcare, and they are more likely to receive poorer care.

A 2018 report from the Learning Disability Mortality Review Programme found that people with intellectual disabilities also die a lot younger. On average, men die 23 years earlier and women die 27 years earlier compared with the general population.

Our latest study adds to the evidence of these health inequalities. It shows that many people with intellectual disability, who can make decisions about their everyday life, aren't given clear information about their medication. As a result, they often don't understand the drugs prescribed for them or their potential side effects.

Legal consequences

The Accessible Information Standard states that all organisations providing NHS care and publicly funded adult social care must ensure that people with intellectual disability receive information in an

Authors



Claudia Carr

Senior Lecturer in Medical Law and Ethics,
University of Hertfordshire



Silvana Mengoni

Senior Research Fellow, University of
Hertfordshire

accessible format, for example, in easy-read material or pictures. Critically, this also applies to medicines. There are now legal consequences for those who don't comply.

In 2015, the Supreme Court case of *Montgomery v Lanarkshire Health Board* redefined the law on informed consent, putting the patient at the heart of any discussion with a healthcare professional. The judgement states that all healthcare professionals are legally obliged to ensure that patients with the capacity to consent are made aware of the risks of medical treatments. Healthcare professionals who breach this duty can be sued for negligence. Yet, as our study shows, people with intellectual disability are not routinely told about their treatment or the risks it entails.

We found that people with intellectual disability often don't understand when and how to take their medication, and they don't understand the potential side effects. This is a significant problem given that 75% of people with an intellectual disability are prescribed drugs compared with 59% of those without intellectual disability.

It is important that the person who is prescribed the medicine takes it as intended by the prescriber. Taking too much or taking it too often may mean that the medicine will not work as well and can increase the risk of side effects.

Some of these side effects may not be immediately obvious and may only become apparent with regular medical tests. It is also essential that the patient is told how to report any issues with their medicines, which could include the medicine failing to work as expected, side effects and problems in taking the medicines, such as difficulty swallowing, which is more common in people with intellectual disabilities.



The Supreme Court redefined the law on informed consent. Willy Barton/Shutterstock

Reducing health inequality

Some things that people with intellectual disabilities say help them to understand their medication include using simpler language, as well as pictures and videos. This helps people understand why they need to take their medication and how to use it correctly.

The Supreme Court decision in Montgomery specifically states that information must be given to patients in a way that they can understand. In doing so, the patient will be able to understand the seriousness of their condition, the risks of any suggested treatment or alternatives, and then provide informed consent. And it is important that healthcare professionals speak directly to the person with intellectual disabilities, not just the carer.

A key message of our research is to put people with intellectual disabilities at the heart of the health service – a message which is now supported by the law. Sometimes this might mean that healthcare professionals will have to spend longer explaining their medication, use different resources, and explain things in simpler language. This will help improve the lives of more than a million people in the UK with an intellectual disability and make a significant contribution to addressing the current health inequalities.

 [Law](#) [Intellectual disability](#) [NHS](#) [health inequality](#) [Prescription drugs](#) [Supreme Court](#)