

# Rowen Jade obituary

Determined adviser to the government on disability matters



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- **Jane Campbell**
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Jade's trademark was her ability to challenge long-held views about disability in ways that people could understand

The disability rights leader Rowen Jade, who has died aged 40 from a chest infection, was pivotal in communicating the views of disabled people to those who hold the purse strings and determine the policies that affect our lives. As chair of Equality 2025 from 2008 onwards, she was the chief adviser to the government on disability matters, and thus held a key position in influencing ministers and civil servants. The disability movement's mantra – "Nothing about us, without us" – was in safe hands with her. She communicated the experience and dreams of disabled people with great accuracy and unconditional humility.

Born Sharon Mace to Bob and Janet Mace in Oxford, she had a very severe form of spinal muscular atrophy. Typically, doctors predicted she would not live beyond a few years. Indeed, anyone meeting her for the first time, as she lay like a delicate feather in her chaise-longue style wheelchair could be forgiven for thinking: "How does she survive?"

Of course, this apparent frailty was part of her power and gave her a unique ability to challenge stereotypes of disability. She could hardly eat, breath or move and never weighed more than three stone. Yet she had the physical and mental strength to achieve so much.

Thanks to the determination of her parents, she attended a mainstream school, Lord Williams's school in Thame, where she thrived. At Oxford Brookes University, she achieved a double first in English and law. On leaving, she decided a career in law was not going to feed her creative side, although she was a fierce advocate of social justice. Her first job in disability rights consisted of running empowerment projects for disabled children at the Alliance for Inclusive Education in London.

I first met Rowen in the early 1990s, when she was instrumental in setting up an organisation of disabled people in Oxford. I remember thinking that she was somehow motionlessly hyperactive. This paradox made her a unique human force. Rowen's trademark was her ability to challenge long-held views about disability in ways that people could understand and accept. Her honest, gentle approach, taking care of everyone she met (especially those who did not agree with her), made her the perfect disabled persons' advocate.

The early 1990s was also the time when she became involved in the campaign for independent living and the use of direct payments to enable disabled people to employ personal assistants, instead of being dependent upon local authority services. As someone who needed 24-hour support, she clearly described the power relationship between the assisted and the assistor: "If you do not have choice and control over the person who is assisting you, you never have real control over your life. Having PAs enabled me to find out who I am and now enables me to be who I am."

In 1996 she took the name Rowen Jade. Three years later, the Alliance for Inclusive Education published the report she co-authored with Christine Wilson, *Whose Voice Is It Anyway?* It captured the experience of young people in special and mainstream schools and was highly influential, much of it finding its way into the government white paper *Every Disabled Child Matters*.

After moving to Bristol in 2000, Rowen joined the West of England Centre for Inclusive Living (WECIL), where she pioneered extending the provision of independent living services to disabled teenagers. Around this time, Rowen and her partner, Jaz Ishtar, decided to have their own child, Olivia, conceived by Jaz through insemination. Rowen's love of children inspired her to write, with Michelle Waites, *Bigger Than the Sky* (1999), about disabled parenting, to combat prejudice against disabled people becoming parents, and it included her account of the experience of conceiving Olivia that she had shared with Jaz.

Rowen was "out and proud" both as a disabled person and as a lesbian. An active member of many support and campaigning groups, she was one of the first disabled people to speak out against a change in the law on assisted suicide and, in 2006, becoming a founder member and passionate supporter of Not Dead Yet UK. She asked the question, "Why are people so keen to help us die, when what we want is support to live with dignity?"

Rowen personified the art of the possible and a belief that "the meek shall inherit the earth". She died while on holiday with Jaz and Olivia, who survive her.

- **Rowen Jade, disability rights activist, born 1 December 1969; died 2 September 2010**