

# Speaking out

With an election happening in the UK, Mary O'Hara reports from the States on how activists there are lobbying politicians to put mental health on the agenda across the pond



## Robert Villanueva wants a rethink on mental illness

Listening to Robert Villanueva, it isn't difficult to see why he is such an adroit public speaker and why he inspires so many of the people he comes into contact with. A native Californian, athletic, tanned and with a broad, warm smile, the candid way he has of communicating his experience of mental illness and how it has shaped the way he sees the world, is disarming. What is needed, he suggests, is a society-wide rethink of how mental illness and those living with it are viewed.

### Stigma persists

'What I find is that people are okay with being a recovered addict, but when it comes to mental health I guess that notion that you don't recover, that you have to live with it, sticks.

'A perfect example is someone will say "I've been sober three years" and there's a certain amount of accomplishment [in that]. And there's maybe applause in the room. Whereas someone says "I haven't been in the hospital for two years" and it's not seen as an accomplishment. It's very much "oh okay, well let's hope there's not another time".'

Villanueva says he has come 'a very long way' from the period when, as a happy family man with his own business, he had a breakdown that would eventually see him diagnosed as being bipolar. It was tough but his journey from near destitution (he lost his business and his family and was living in a friend's spare room for months before finding help thanks to a peer support group) to the advocate he is now, 'completely' altered his life.

### Increasing awareness

Villanueva is a speaker for the In Our Own Voice programme run by the National Alliance Mental Illness (NAMI), America's largest and most enduring mainstream mental health advocacy group. He is one of 100s of people with a diagnosis, speaking publicly and regularly at forums, community centres and other venues about his experiences.

The programme is just one high profile example of the multitude of diverse initiatives across the United States trying to engender a greater understanding of what it means to have a diagnosis and to combat stigma and ignorance.

Many such projects are designed merely as support networks for 'consumers' (as service users in the US are frequently called) and their families, while others have explicit goals for informing the public as well as lobbying policymakers.

### Diverse country, disparate ideas

In a country as vast and as heterogeneous as the US, a myriad of local, regional and national approaches to influencing policy and changing attitudes have emerged. The distinctive character, culture and laws of each of the 50 states often produces radically disparate ideas about not only how to campaign but what to campaign for.

Add to this the fact that for many mental health campaigners NAMI is not their chosen advocacy route (one of the reasons cited is the organisation's willingness to accept funding from pharmaceutical firms) and what quickly emerges is a complex, evolving landscape of competing ideas and strategies.

Mental health advocacy in the US is so broad and diverse – and fluid – that it would be impossible to do it justice in a single article. But there are still lessons the UK can learn from what is happening there.

### In California

Tom Wootton, an outspoken Californian with a diagnosis of bipolar, cuts a controversial figure in the advocacy arena. An author and public speaker, his latest book, *Bipolar In Order*, espouses his theory that it is possible for many people to adjust to their symptoms, rather than feel compelled to escape from them through, say, medication. Wootton accuses many 'well-meaning' advocates, professionals, friends and family members of a 'can't do' attitude that reinforces stigma – and he attracts considerable criticism for it.

In San Francisco, the recently formed local organisation No Health without Mental Health (NHMH) has national ambitions. Set up by Florence Fee, a corporate executive whose brother took his own life because of difficulties compounded by post-traumatic stress disorder following the Vietnam war, NHMH is a communications and marketing group with a mission to 'demystify and humanise' mental illness. Fee says she wants to see an informed and open public discussion.

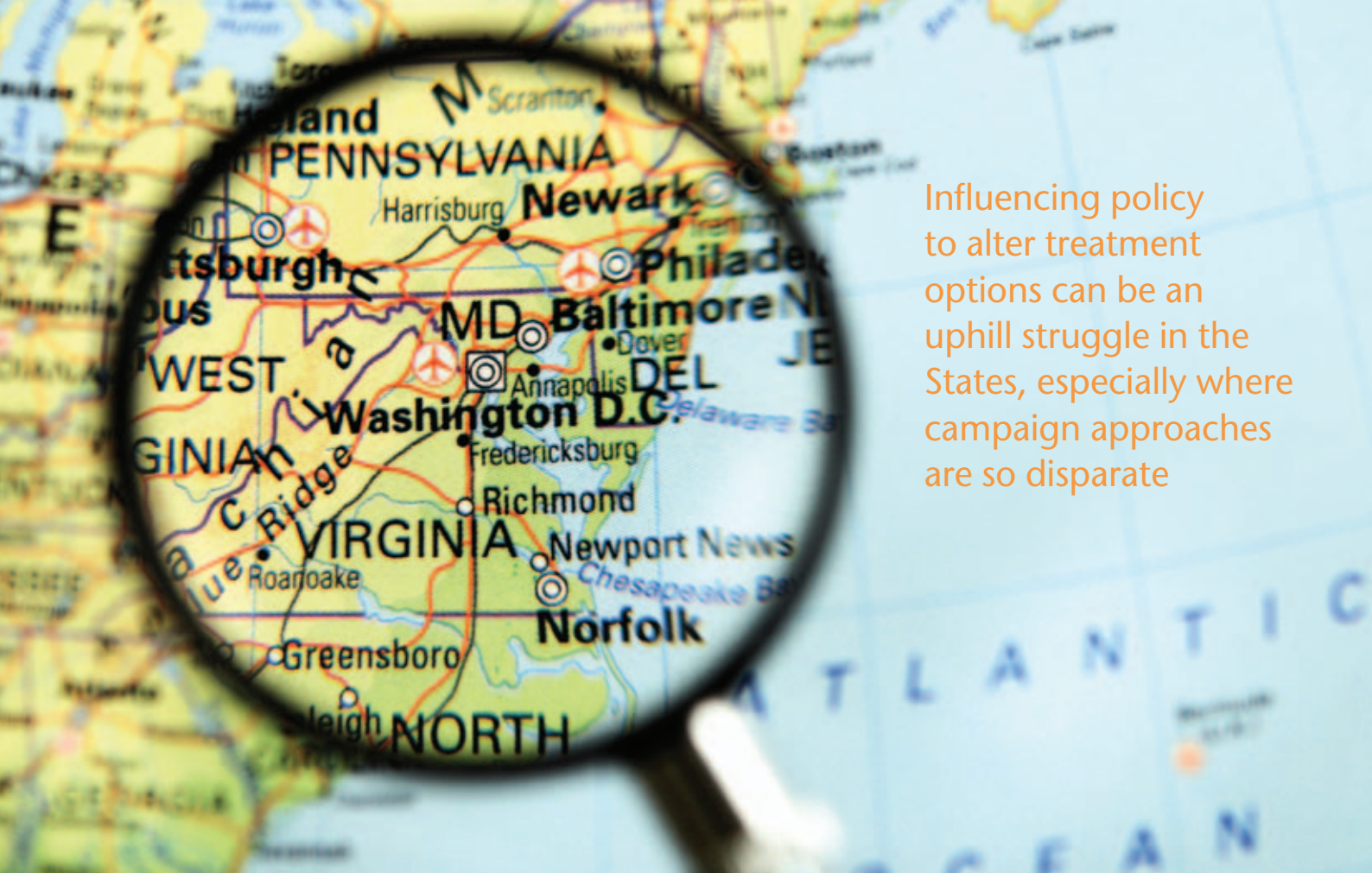
### In the Pacific northwest

Further up the west coast, in Portland, Oregon, is Will Hall, a young campaigner with a diagnosis of schizophrenia who runs an innovative media project, *Madness Radio*.

Hall, along with a number of campaigners, believes that in the past ex-patients benefited from forming alliances with the wider civil rights movements. The campaigners argue that much more needs to be done on, for instance, challenging the medical model of treatment and the influence of pharmaceutical companies.

'In the UK, the user movement is more recent and has not

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Influencing policy to alter treatment options can be an uphill struggle in the States, especially where campaign approaches are so disparate

undergone quite this dynamic,' says Hall. 'The movement [here] came very simply out of people being harmed by the mental health system. The three sources of harm are forced treatment, diagnostic labelling, and medications. That's what [still] needs to be addressed that isn't.'

### On the east coast

On the east coast, in Massachusetts, campaigner Dan Fisher, co-founder of the National Empowerment Center (NEC), is proving to be one of the most effective advocates at influencing policy directly. NEC is a not-for-profit organisation that provides emergency 'respite' care for people in crisis and directly challenges the over-prescribing of medication.



**Dan Fisher is a vocal campaigner, service user and also a psychiatrist**

A psychiatrist who was diagnosed with schizophrenia in his early 20s and vocal champion of the recovery model (see: *The American Way, Mental Health Today*, February 2010), Fisher has been accused by some critics in his own profession of being an example of patients' rights run amok. Fisher earned his activist stripes in the militant patients' rights movement of the 1970s and has for 20 years been challenging the idea that medicine is the 'primary tool' for treating people in mental distress.

### Change is needed

Recently, thanks largely to alliances with the disability rights movement in the US and consulting for the Obama administration since it was elected, Fisher has a seat at the table with the people responsible for shaping

future policy. He is hoping, even if only incrementally at first, that the idea of peer support as a valid form of treatment is understood, embraced and adopted.

There is a real sense of – as Fee puts it – 'flux' in the mental health sector in the US right now. Debates range from the philosophical to the intrinsically pragmatic. Many of the issues that emerged decades ago as a consequence of the patients' rights movement, such as high levels of street homelessness produced by the closure of large mental institutions, are still relevant today. But there is a bigger picture that must be taken into account according to Fisher.

'Even for a very well-meaning professional or person who doesn't have a disability, it's very hard for them to grasp this movement and to grasp the enormous need for deep-seated change.'

### An uphill struggle

The modis operandi of mental health advocates in the US are, then, at best, disparate, and at times, contradictory or controversial. Influencing policy to alter treatment options can be an uphill struggle, although occasionally a notable national victory is achieved.

When, as someone who was diagnosed bipolar, congressman Patrick Kennedy, began pushing mental health parity as a civil rights issue in Washington, along with his father Ted, policymakers began listening. With others, they helped push through legislation that required equal coverage of mental and physical illnesses by insurance companies, which was widely regarded as a landmark achievement.

But Villaneuva, true to erudite form, sums up what for many is the reason they got involved in the first place: their conviction that more change is necessary.

'I want a public discussion,' he says. 'Whether that's in a church or at a union meeting – I want a discussion.' ■