# Debate & Analysis The James Mackenzie Lecture 2012

Bothering about Billy



I first read Simon Armitage's poem, A Painted Bird for Thomas Szasz,1 over 20 years ago. I was a new GP in Birmingham, and drawn to it because it was written by someone about my age, a probation officer, a practical poet connected to the real world. Most of all, his description of Billy, a rough sleeper with a serious mental illness, made sense to me. He described seeing and being bothered by Billy at a local bus station, 'talking to the drivers who ignored him', in an arcade smelling 'like a wet dog, drying', and 'in the covered precinct pissing himself through his pants onto the concrete'. I saw Billy most weeks at the Summerhill Day Centre where my practice ran a drop-in medical service for anyone homeless in the city. I used to start each consultation by asking people why they'd ended up needing to come to Summerhill. I heard stories of unemployment leading to divorce and rooflessness; of too much alcohol; of a life led in institutions, in care, or in prison; or in the army then discharged onto the streets; and above all, for about half the people I spoke to, I heard stories of teenage 'breakdowns'. I was also left with an unshakeable impression that psychosis was something that primary care could and should engage with, and, if I had anything to do with it, would engage with.

In this 2012 James Mackenzie Lecture, I'm going to argue that people with psychosis have poorer health and social outcomes than the general population; that this is related to a range of issues including negative stereotypes of people with psychosis; and in part because of poorer primary care but that primary care is ideally placed to provide first rate health care for people with psychosis. Finally I'm going to describe some of the things that we could do simply and easily to improve the health and health care of people with psychosis.

Let's start with the basics, life expectancy. A recent paper by Wahlberg<sup>2</sup> found that men with serious mental illness live 20 years less, and women 15 years less, than the general population. Chang's paper, with data on over 31 000 people with serious mental illness in London in 2009<sup>3</sup> had very similar findings, representing a 'scandal of premature mortality that contraveness international conventions for the "right to health". '4

Some of this excess mortality is related to higher than expected suicide rates, however, about two-thirds is explained by physical health problems, largely heart disease, stroke, and diabetes, themselves of course related to a complex web of risk factors including smoking and obesity. Approximately two-thirds of people with serious mental illness smoke.<sup>5</sup> Some of the obesity is related to sedentary lifestyles, poor diet, and ultimately to poverty. Obesity is also linked to the side effects of antipsychotic medicines. Adverse changes to blood glucose and lipids happen aggressively and early on and some young people gain up to 10 kg in weight within 12 weeks of starting a new tablet, a simultaneous fattening and flattening of self-esteem.6,7

Given these issues, why doesn't primary care see the health and health care of people with psychosis as part of their core business? This, too, appears to be multifactorial. Let's start with the inverse care law:<sup>8</sup> that the availability of good medical care tends to vary inversely with the need for it in the population served. There is plenty of evidence that people with serious mental illness receive poorer primary health care than the general population despite the fact that they are at a far higher risk of developing a range of physical illnesses.<sup>9-11</sup>

There's also evidence that some GPs simply don't accept that the care of people with serious mental illness is their business; that unlike people with diabetes or heart failure, they are too complicated.<sup>12</sup> Many GPs are adamant that they don't possess the right skills to provide care for people with a psychosis beyond continuing prescribe medication started in to secondary care and maybe some physical health checks. GPs are also not immune to the negative stereotypes and stigma of mental illness. Goffman talks about stigma as an 'attribute that is deeply discrediting' that makes the person carrying it 'different from others and less desirable (page 3). An awareness of the attribute then results in the belief that 'a person with a stigma is not quite human'. (page 5).13

Given this context, it's little wonder then that students and doctors view mental health as a low prestige condition<sup>14</sup> and that medical students' attitudes towards people with serious mental illness become more negative the nearer they get to qualification.<sup>15</sup> Above all, many see serious mental illness as a condition from which you can never recover despite the fact that we now know that at least 15% of people make a full recovery and about 50% overall have a good outcome in terms of a social recovery.<sup>16</sup>

Stigma can creep and seep into the everyday interactions of the best intentioned. Eight years ago, I was running a series of lunchtime focus groups with people with psychosis and GPs in community venues across the West Midlands. A GP, a mental health lead for her primary care trust, turned up, filled her plate with sandwiches, and sat down by me. 'Oh' she said, looking around the vestry at the group, 'I see I'm the first person here.' It was a slip of the tongue. She meant of course that she was

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the first health professional there. But the words reflected a mindset that somehow, as Goffman suggested, people with serious mental illness are not quite like us.

So to summarise, for a variety of reasons. particularly stigma, many GPs don't see the care of people with serious mental illness as their core business. However I would argue that in fact it absolutely is our business and we already have all the basic building blocks we need to provide high quality primary care. We practise our trade in a low-stigma setting that is easily accessed in a crisis and at most other times too. We are experts in generalism, prepared to be interested in everything.<sup>17</sup> Our consultations involve handling uncertainty, avoiding overtreatment, and detecting potentially serious conditions at an early stage. We provide 'cradle-to-grave' care through 10-minute consultations over decades, enabling interpersonal continuity to build in a way that no other part of the health service can. We work with a team of highly skilled nurses for whom management of long-term physical conditions, weight management, and smoking cessation advice are core activities. In other words, primary care is both a setting and has a workforce that is ideally suited to providing care for people with serious mental illness. During the last 30 years we have, in fact, almost without noticing, taken over the care of people with serious mental illness. Over 70% of patients are now largely managed by primary care, making it very much our business.<sup>18</sup> Most service users also describe primary care as the cornerstone of their care.<sup>19</sup> People want an advocate and system navigator at times of crisis. They value the fact that the GP has known them for years, knows the family background, knows them when they are well and, in contrast to secondary care, that they don't have to retell painful stories to new doctors every 6 months. They value the GP simply being there, to listen to their madness.

Finally, let me demonstrate how by doing just a small number of things a little differently, we can improve both the health and health care of people with serious mental illness. Twenty years ago, people with serious mental illness saw their GP about 13 times a year.<sup>20</sup> Now it's closer to three, only just very slightly more than the general population.<sup>18</sup> I don't think this reflects a reduction in need but rather problems with access.

So what can we do? We can red flag notes for receptionists so the 20 people on each GP's now nominal list can have easier access to a GP who knows them. We can offer waiting space outside the doctor's door so noisy consulting rooms that exacerbate symptoms are avoided. We can give slightly longer appointments or the last-of-the-day appointments. None of this is rocket science. People with serious mental illness, with their growing number of physical health problems, also underuse practice nurses, consulting them on average only once a year, half the rate of the general population. Only 18% of those nurses have received any sort of mental health training.<sup>18</sup> So should we train more of our practice nurses in mental health issues and then encourage them to use these and their excellent physical healthcare skills in mental health reviews?

We also perhaps need to look at the outcomes of those reviews. We may dutifully record the body mass index of 33 and smoking habit of 30 a day but then what do we do? I'm pretty sure many of us stop there. So we need to adopt a new mantra for people with serious mental illness, that we don't just screen, we intervene using evidence-based algorithms<sup>21</sup> and from an early age. We need to explain about the side effects of atypical and typical class drugs so young people can make an informed choice about taking them. If they do decide to do so, then we need to chat through side effects honestly and openly, intervene early to prevent weight gain,<sup>22</sup> and encourage them, where relevant, to stop smoking.<sup>23,24</sup>

We need to support families too. Ongoing work as part of the SUPEREDEN programme grant is highlighting the importance of asking mum and dad about how they are coping with the trauma of a new diagnosis. Carers identified 'layers of listening', with health professionals listening differentially and zoning in on issues that were of immediate relevance to the patient but not perhaps the carer.

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They talked about the terrible stress and strain the illness put on them and their relationships and the need to have a dispassionate but informed listening ear. Surely we have a role here? Perhaps, above all, we need to remember that we can be the holders of hope. We need to say repeatedly at the start of the illness that 50% of people make a good recovery.

So in summary I hope this lecture has helped you reflect that the health and health care of people with serious mental illness is our business. I hope you feel that people with schizophrenia and bipolar disorder need better care than they currently receive. I hope you see that there are many things that cost little, that are based on simple observations not rocket science that we could introduce tomorrow into routine general practice. But above all, I think, if we examine our hearts, it boils down, quite simply, to being bothered about Billy.

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This text is based on the James Mackenzie Lecture delivered at the Royal College of General Practitioners Annual General Meeting, London, on 16 November 2012.

The full lecture can be accessed on YouTube: http://www.youtube.com/watch?v=tqyACm50QOM

# Provenance

Commissioned; not externally peer reviewed.

### ©British Journal of General Practice

This is the full-length article (published online 25 Feb 2012) of an abridged version published in print. Cite this article as: **Br J Gen Pract 2013; DOI: 10.3399/bjgp13X664414** 

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