**Transforming Care - A Panoramic View of Recent Events in Learning Disability**

It is customary to bemoan the fact that the BBC’s flagship for investigative journalism, Panorama, is not what it was. And that’s because it isn’t. But sometimes it does get something right, and there is no doubting the power of its 2011 expose of poor care and severe abuse at Winterbourne View. What now follows is an account of what happened next. It’s a bit of a long story, but stick with it, even if you are not involved in learning disability (LD), because we hope you will see there are lessons for us all in the story.

OK, “Winterbourne View” set in motion a complex sequence of events. The first response was predictable, a knee jerk crash programme of accelerating discharge from learning disability inpatient services to achieve a dramatic reduction in national bed numbers. And the result was equally predictable. Short term success, but soon many were being readmitted, leaving the situation in status quo ante, with the same number of beds as before.

So now, enter Simon Stevens, the new head of NHS-England. And to his credit, one of the first things he did on taking office was to make it a personal priority to achieve some real change post Winterbourne View – indeed soon after both of us had taken up our new roles, Simon S trapped Simon W at a social reception to ask how we could improve the situation. Simon W immediately turned to AR and his colleagues in the Learning Disability (LD) faculty who rose swiftly to this challenge. At the same time, Simon S asked Sir Stephen Bubb, who is the Chief Executive of the voluntary sector equivalent of the NHS Confed (in other words represents the voluntary sector charities) to provide recommendations on steps to accelerate change. Or, if you prefer, to give everyone a kick up the back side; which he duly did.

Publication of his report in November 2014 marked an important step in realising that simply discharging long stay LD patients in an unplanned and uncoordinated fashion was not going to work. Instead, it led to the development of the Transforming Care programme, bringing together NHS England, Department of Health (DH), CQC, Health Education England (HEE), the Association of Directors of Adult Social Services (ADASS) and the Local Government Association (LGA) to form a Delivery Board to deliver on five work streams (Care in a new model, workforce, information, partnership working and regulation. Progress since the launch of this programme in February 2015 when Simon Stevens appeared in front of the Health Select Committee is summarised below,

1. NHS England, in partnership with the LGA and ADASS, lead on the delivery of the “the right care in the right place”. This has led to the development of a new model of care which would result in a partial closure of beds and the strengthening of community services which reduces admission of people with mental and behavioural problems. So far so good, although a new draft appeared this week - the final version is not expected till October. NHS England, along with CCGs, are also commissioning of Care and Treatment Reviews (CTRs), which bring together commissioners, clinicians (many drawn from the LD Faculty) and Experts by Experience (carers and former service users) to challenge the reasons why people are still in hospital. Around 2000 CTRs have been completed, leading to an increase in discharges.

NHS England is giving extra support to five ‘fast track’ sites to transform services.

The five areas are: Greater Manchester and Lancashire; Cumbria and the North East; Arden, Herefordshire and Worcestershire; Nottinghamshire and Hertfordshire. They will get support from NHS England to make plans over the summer, and access to £10 million to speed things along. This will also help shape the approach NHS England takes to transforming learning disability services – which does have a familiar ring to it. Co-producing the central support provided to bring about change, implementing the model of care, national planning for in-patient and community based services, ways of using public money more flexibly to get the best outcomes, building on co-commissioning arrangements between NHS England, local NHS commissioners and Local Authorities, and promoting personal budgets are now being pushed forward at pace. A personal budget to purchase services, by the way, is something else that Simon Stevens had been championing on many occasions.

1. Future Service Model - NHS England is developing a ‘service model’. This is mainly for NHS and social care commissioners, to help them understand what kind of services they should have in place, what the purpose of these services is and what outcomes they should be achieving, ‘how much’ of different types of services they should have in place and what standards they should ensure those services meet . Of course, since Lansley’s Monster, as the 2012 Health and Social Care Act is affectionately known, NHS-E can’t actually tell anyone what to do, but instead provides guidance, which commissioners will be encouraged to follow. The five fast track areas will plan changes over the summer and test the model. Plans are due to be submitted by early September. Clearly no one is going on a summer holiday this year.
2. NHS England and the Health and Social Care Information Centre (HSCIC) have produced a lot of data to monitor progress, which is called the “Assuring Transformation” data set. One does wonder where they get these names from. Anyway, it provides inpatient numbers, admissions and discharges at national, regional and commissioner levels and lengths of stay. And to be fair, it is now clear that numbers of inpatients is now going down, albeit slowly. In March 2014 it was 2615, and the latest information has 2,475 patients in inpatient settings a year later. Work also has started on how national and local information can be used to identify people (thought to be about 24,000 in England) considered to be ‘at risk’ of being admitted to hospital for assessment and treatment.
3. Sharing Confidential Information. Apparently, one barrier has been difficulties in sharing confidential data about patients between health and social care and indeed within health and social care. Gosh, who would have thought that, apart from everyone who has been talking about the issue for years. Anyway, let’s not look a gift horse in the mouth, because a “Consent Working Group” has been set up to develop guidance. A Consent Form is being developed for patients involved in the Transforming Care programme so that information about them can be shared for commissioning and planning. And if you don’t get consent, or if it’s not valid, what then? The sooner we start to rethink our approach to data protection the better, says one of us, jumping onto his hobby horse once again.
4. Sir Stephen Bubb had a follow up meeting with all the stakeholders in July. He felt that pace of change had been slow. Time for more backside kicking. He recommended that the new Government should introduce new legislation to enshrine “the right to challenge” in law so that people with learning disabilities and their families are truly empowered to question the care they receive. Now, recognising that this was not just a health issue, nor a social care issue, but also a criminal justice issue, he has called for a cross governmental response. He called for a hospital closure programme to be published by October. He further recommended the establishment of an independently chaired Transition Taskforce who will take practical steps to establish improved community capacity. Finally, he wanted the government to increase the powers of the CQC to provide again of additional protection to people cared for in supported living.
5. In July, reports published by Public Health England, NHS Improving Quality and the CQC provided evidence that people with learning disabilities were being overmedicated with psychotropic drugs often for the management of disturbed behaviour when there is no evidence of efficacy and often no valid mental illness diagnosis. The ID Faculty has always made it clear its antipathy to this pattern of prescribing – we know already that one in six adults with LD are already on psychotropic medication before they reach secondary care. The Faculty, along with the Royal Pharmaceutical Society and the RCGP, is leading a call for action involving all stakeholders to significantly reduce overprescribing and to implement alternative treatment strategies in a spirit of partnership with people with learning disabilities and their carers. The Faculty has advised NHS England to integrate this work stream with the development of its forthcoming model of service.
6. So what is the current situation? Learning Disability services are now in the throes of rapid and sustained change which will improve the quality of lives of people with a learning disability and result in improvement in working practice and in training and development of the workforce. Health Education England and its partners are leading this work stream. It is likely that in the community based model of services the number of psychiatrists will increase.

Last words. As a group LD Psychiatrists were scapegoated after Winterbourne View, unfairly blamed for the poor quality of care that undoubtedly existed in some settings. But far from being a barrier to progress they have been proven right for championing good community services as a prerequisite for bed closures.

Ashok Roy, Simon Wessely

22nd July 2015