Ymchwiliad i Fil Iechyd a Gofal Cymdeithasol (Ansawdd ac Ymgysylltu) (Cymru) Inquiry into the Health and Social Care (Quality and Engagement) (Wales) Bill Ymateb gan Unigolyn

Response from an individual

Health and Social Care (Quality and Engagement) (Wales) Bill

In response to the committees request for comments on the principle of the bill, I hope my personal views outlined below may helpful to it.

I have been a patient of the NHS, with a chronic endocrine disorder for almost 50 years, and have recently retired from working in the NHS after 40 years. Some 30 years ago I had quality of life restoring surgery (relief of spinal compression, with paraplegia), and 19 years ago life saving heart surgery. Thus, I have seen the service from both sides as both patient and professional. I remain an outpatient of a specialist service. I have also observed, as an interested and concerned party, the services provided to my spouse and children and more recently grandchildren in various countries and areas.

The bill targets three basic problems.

- 1) A perception that quality of service is not improving as fast as it could.
- 2) A perception that when things go wrong everything is covered up.
- 3) A perception that patients' views are not being adequately/properly listened too.

Taking each problem in turn:

Quality Improvement.

The Bill proposes imposing a statutory duty to improve services. This Section of the act is perfect in intent.

However, it both fails to offer any action if Health bodies fail to achieve this nor does it suggest how Boards should achieve improvement, nor over what sort of timescale they will be evaluated.

- a) Experience suggests health bodies will respond by developing even more procedures and processes to prevent patient centred care! Instead imposing a one size fits all approach, based on National Guidelines, in order to have someone to blame when things go wrong. (Slavishly following National guidelines, based on the notional 'average patient' ensures that no patient receives optimal care! Ensuring harm and waste in the system.)
- b) As perception that services are deteriorating despite:
 - 1) All registered staff already have a requirement to improve care in their ethical codes and
 - 2) There is no evidence that health care professionals are commonly in breach of these ethical codes and
 - 3) Health outcomes as measured by aged standardised mortality are steadily deteriorating, for the first time since the NHS began!

suggests health bodies have been, presumably accidentally, preventing staff from carrying out this duty! Thus, the omission of personal sanction against the Board members, and executives in particular, of Health bodies is a serious and potentially life threatening for some patients.

c) How HB are to improve is not mentioned. But current methods are not working. Perhaps regulations should be required by the bill, to provide guidance based on empowering the professionals employed by those bodies is needed, not relying on remote centres to 'helicopter in' experts! The guidance MUST NOT be, do more of the same, only better! The guidance ought to be mindful of Fisher's fundamental law that the rate of improvement to optimise fitness is proportional to the variation in the individuals. So attempts to reduce observed variation will inevitably reduce the quality of service available to individuals.

The Duty of Candour

The duty of candour sounds fine in principle, but reality suggests it hinders education and improvement. Indeed, last century Dame O'Neil raised concern that more candour may paradoxically, lead to greater secrecy and less trust; events suggest her analysis was and remains correct.

It appears if you trust people: they trust you to keep secrets and so they are open with you. Hence the effect of imposing a duty of candour may lead to increased secrecy.

The effects of numerous inquiries into children's social care adverse outcomes have not prevented the same problems recurring, despite increasing prescription of social work. Thus it is important that this duty should not become a 'tick box' exercise.

The Bill once again proposes no action that is to be taken, against those in charge, if a body fails in this duty. Thus, it is highly likely that individuals, who were treating the individual will be blamed, and publicly admonished, perhaps even losing their livelihood.

Furthermore, if improvement as required in Part 2 is required, them ALL individuals involved in the care must, except in exceptional circumstances, be protected against publicity and professional punishment. Only those running the organisation should, in general, be held both personally, professionally and publicly responsible for failures of the health body, in common with President Truman's maxim "the buck stops here!"

The bill should require regulations explaining in defining what is a trivial adverse event. Otherwise, good organisations seeking to genuinely improve care could be overburdened with producing reports, most of which will not result in any systemic change.

Additionally, care must be taken to ensure that the administrative burden this duty places on individual and small contractors in primary care, does not result in the increasing the shortage of people willing to renew and enhance the primary care network of care. At present, the additional work of reporting for the end of the financial year, could be an additional load on a service already spending too much time not doing what it is principally contracted to provide, instead ensuring it meets obligations to provide documentation, rather than face to face activity.

A new Patient representative body.

Having a body that acts as a local advocate of patients and local authority service users is essential to assist health and care services to respond to the needs of LOCAL populations. This has always been a function of the CHC's, and, as Health and Social care are interlinked, having a single body to address these is sensible.

CHC's could be effective locally in the past, if health care providers were willing to both listen to and after consideration of, act on their suggestions. The proposed Citizens Voice has the right to raise issues as it wishes, with any health body, and that health body must give this consideration. Whilst, this is a welcome change; it remains uncertain if either LA's or LHB's and Trusts will actually change anything as a result!

My personal experience of having the support of my CHC, as a patient, suggests that though the LHB responded and agreed that the issue I raised was important, my case being supported by all the staff directly involved, no hospital wide or even department wide change put in place.

However, since CHC's were brought into unified national body with outposts, to appear local, their limited effectiveness seems to have reduced. I do therefore, wonder how replacing the current ineffective bodies, with a smaller even less representative one will work.

Why cannot the laudable aim of setting up of citizen's voice (with all its inevitable inherent costs) could not be achieved simply and economically by re-instating the local structure of CHC's and incorporating social services users within their purview as well: by a simple amendment as proposed for health bodies in part 2 of this bill.

Conclusions.

The aims of the bill are desirable and very welcome, but it is unclear if the actions it seeks to enact will achieve them. Some possible clarifications have been indicated in each section above. The bill should, in addition, be amended to incorporate:

- A requirement both to develop and to regularly review regulations to ensure uniform and suitable interpretation of the terms used in the bill. In particular, to define how quality is to be measured. This must not simply be process measures, as this hinders patient centred, prudent care chosen wisely.
- A definition of what period and by how much quality will be expected to improve to prevent sanction of the board.
- Finally, the bill should be amended to require the Cabinet Secretary/Minister to indicate how great an effect this and any subsequent NHS or Social Care act, will create on these concerns i.e. conduct a predictive quantative Health Impact Assessment. Additionally, the assembly must require the government at a defined future date to report to the assembly a systematic evaluation, using standard scientific evaluation methods as outlined by NICE, on the effectiveness of these changes after 5 to 10 years.

I hope this is helpful.