

Building Blocks - some missing
Hope you're enjoying yours
Pete Johns
Tommy Morgan

~~Wag~~
~~celebrate~~

ACHCEW Conference – The Golden Age of Public Involvement

Thank You Alan and a special thank you to our excellent guest speakers.

- ◆ I am very glad and honoured to be here today
- ◆ Before becoming director of ACHCEW I worked in Southwark CHC in South London for 15 years and like you have experienced the anger and frustration of Alan Milburn's meanderings through the new PPI system
- ◆ The negative attitude of the Government towards our great achievements over 28 years has caused despondency and despair.
- ◆ Why destroy a great movement when transition and transformation to CPPIH and PF would be so sensible, so logical and have achieved our objectives.

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We've been through a lot in the past three years

- ◆ Following the decision to extend the life of CHCs to December I received some very disturbing and angry emails from CHCs across the country – some of them almost melted my hard drive.
- ◆ Now DH know how you feel and it's up to them to deal with the many issues you have raised about the abolition of CHCs in a compassionate and indeed generous way.
- ◆ We have been fantastic, we have achieved so much for patients and the NHS
- ◆ The Government owes us respect and gratitude for our outstanding achievements in patient and public involvement.

Lets go back to the beginning

- ◆ **When CHCs were born the idea of patients rights and the duty of the NHS towards patients and carers (yes carers—) was in its infancy**
- ◆ **Resolving the tension between patient power and the power of NHS professionals, has been a key role for CHCs**
- ◆ **CHCs have worked at the coal-face, operated with the legitimacy created for us by parliament and have become experts in every area of patient and public involvement.**
- ◆ **The NHS now boasts of being ‘patient focussed’ and claims to have put the patient at the ‘ heart of the NHS’.**
- ◆ **But their commitment to PPI grew out of our great movement and our highly successful work with voluntary and community sector bodies. In practice wherever there has been successful PPI the local CHC has been involved.**
- ◆ **The CPPIH, Patients Forums, the new Section 11 powers to involve the public in the NHS and the development of the Overview and Scrutiny committees are all testimony to our success.**
- ◆ **Like an Orange**
- ◆ **The new patients and public involvement bodies have been created out of our achievements**

(2) We have achieved so much – and experienced so much suffering on the way

- ◆ CHCs have been powerful agents of change and have achieved so much.
- ◆ I remember my own disbelief and rage at discovering patients at the Maudsley Hospital 100 yards from the CHC office who had been raped in the wards and ignored when they reported these crimes.
- ◆ A playground attached to a children's psychiatric ward with a dangerous concrete surface and a nurse who told me that the kids in the ward were tough kids used to getting knocked around
- ◆ Trolleys in A and E departments so close to each other that there was no room for friends and relative to hold the hand of their loved ones
- ◆ Miscarried babies thrown into black bags and incinerated without the knowledge or consent of the parents

Now SEEMS Unbelievable – That is because we have created a culture in the NHS where patients are now respected and seen as a priority

And Because:

- ◆ You and your predecessors have probed, explored, listened, demanded and won great improvements for patients.

In the 70 and 80 this included a massive amount of work with the old long stay hospitals.

- ◆ There were long stay patients who had lived in psychiatric wards for over thirty years for committing 'social crimes' and at the age of 60 or 70 had few possessions, perhaps just a teddy bear for comfort
- ◆ There were people with learning difficulties condemned to an infantilised life in the old mental handicap hospitals.

These were amongst the major issues tackled by CHCs and tackled successfully. They are recent history

◆ Sadly in Britain major change usually follows great tragedy

- ◆ Many disasters have hit the NHS
- ◆ Rodney Ledward whose surgical abuse of many women led them to suffer deformity, pain and depression as a result of his butchery.
- ◆ The heart broken families in Bristol who campaigned so vigorously about the deaths of 29 babies
- ◆ Beverley Allitt who killed the patients she was supposed to be caring for
- ◆
- ◆ CHCs were active in all of these distressing situations, supporting the families, demanding answers, calling for proper governance of the NHS and trying to prevent a repeat of these tragedies.
- ◆ Pressure from CHCs has led to major changes in the NHS in each of these areas
- ◆ Sadly arrogance, disbelief, collusion and denial have often been the initial reaction in the NHS to these disasters.

But we have done so much more

We have monitored the NHS, created Casualty Watch and transformed health care and supported the development of new patients focussed services across the country.

And of course complaints work has been of critical importance

- ◆ **For me the most moving experience was bringing a bereaved couple together with the obstetrician they alleged was responsible for the death their baby. The meeting was highly charged. To the couples shock the doctor admitted her responsibility for the death. The parents were able to grieve, forgive the doctor, and start to life again.**
- ◆ **CHC expertise has assisted clients with this type of complaint day in day out all over the country for quarter of a century. Complaints services run by CHCs have been second to none**
- ◆ **The pain and grief of so many CHC clients has been met with understanding, sensitivity, highly effective advocacy, investigation, major improvements in services. and relief to many who have battled with the NHS bureaucracy to get answers to their complaints.**

To achieve so much Independence has been very important

- ◆ **CHCs have jealousy guarded their independence. You can't battle for patient's rights with one hand tied behind your back.**
- ◆ **The new idea is that everyone is now in "the big tent" i.e. the commission and the Government. Of course it is important to be constructive and to have a good relationship with the DH and local trusts**
- ◆ **But sometimes you need to have the courage to stand apart, to be independent. Patients need to have that independent voice.**
- ◆ **That is one of the most important lessons that CHCs have to teach to the new system**
- ◆ **We have also fought vigorously for the independence of the new Patients Forums and the CPPIH, for sufficient resources, real influence and unfettered right of access to all parts of NHS.**

Much Has Been Conceded by the Government

- ◆ **The new Commission is the outcome of our campaign for an independent national body to add weight to the powers of local Patients Forums**
- ◆ **There will be 571 Patients Forums instead of 184 CHCs -**
- ◆ **The Government has conceded the right of access to primary care services**
- ◆ **Complaint's service will be properly constituted as statutory ICAS services.**
- ◆ **So our campaigning work has been a great success!**

- ◆ **But: The new system is being set up in a highly complex way, that will not be easily understood by users.**
- ◆ **With a joint CPPIH/ACHCEW/DH transition plan, new system could have been operating by now. Instead there are delays and confusion**
- ◆ **Alan Milburn's uncompromising approach is responsible for the severe delays in developing the new system**
- ◆ **And for grossly underfunding it.**
- ◆ **The inexperience of those now setting up the CPPIH is understandable**
- ◆ **What is unforgivable is the mess and despondency caused by Ministers mishandling of abolition and transition.**

The Deeply Unpopular Foundation Trusts are another great problem

- ◆ **Alan Milburn made it clear to the Health Select Committee that Foundation Trusts would not have Patients' Forums and that he saw Patients Forums as a temporary measure**
- ◆ **If PCTs get Foundation status PF might fade away altogether!**
- ◆ **Is it rational to replace a generation of outstanding CHC work with a temporary public involvement system? This must be opposed**

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Now we must Prepare for the Future

- ◆ **What has been created by CHCs cannot be destroyed**
- ◆ **We believe in the NHS and that is why we worked so hard to create CHCs**
- ◆ **Why we will be there to defend and extend the rights of patients in the NHS**
- ◆ **We have been great – and we could have created an even greater future**
- ◆ **We've done a fantastic job and we are the people who will inform the new system**
- ◆ **We have created powerful community networks, given people hope where previously there was despair**
- ◆ **created a social movement across the country that is both locally influential and has continuously had a major influence on Government, the GMC, and many other health related public bodies at national level.**
- ◆ **Patients across the country have benefited massively from the highly effective work of CHCs. We have a history and a movement to be proud of; our work is valued across the land.**
- ◆ **The task now is to influence the development of the Commission, Patients Forums and ICAS into bodies that will properly serve the people. There is no going back.**

- ◆ We must build on our brilliant past and help to create new organisations that will empower patients and communities. That will be our true legacy.
- ◆ Without your expertise, experience and knowledge the CPPIH, Overview and Scrutiny Committees and the new Patients Forums will falter.
- ◆ You are the experts, you know how to make the new system work for patients. Without you and our colleagues across the country the new system will take many years to build.
- ◆ There is a job to be done in every part of the country to bring the new system to life. Who better than CHC members and staff to accomplish this great task.
- ◆ Thank you for listening to me, for everything you have done
- ◆ For being here today.
- ◆ I wish you success and happiness for the future

End