

To The Parliamentary Health Committee

A Memoranda Submitted On 8th January 2007 Re:

Patient & Public Involvement In Mental Health The Ethos And Realities And Evolving LINKs

By Paul Brian Tovey

(1)

Introduction

I am giving evidence to the Health Committee from the realistic and mixed patient & public perspective of the longer term patient that has always needed a better more health giving mental health service. I will put forward some views on LINKs by first demonstrating some evolved experience of current practice and its shortcomings which we will all need to guard against in the future. I am also someone who has served with the Birmingham & Solihull Mental Health Patient And Public Involvement Forum as a Deputy Chair and though I left that PPI in 2005 I have continued to work with it informally and provide it with information about the reality of the patient's perspective In Birmingham. I have also continued to provide Dr Lynne Jones MP (one of the Joint Chairs Of the Mental Health Sub Committee) with information demonstrating patterns of poor Section 11 consultation in Birmingham regarding changes and services being varied in several Mental Health Day Centres in Birmingham.

(1/1)

I was more recently liaising effectively with the late Michael Elvin who died in Dec 2006 . He was a Mental Health (MH) campaigner and previous Chair of the Birmingham & Solihull Mental Health Trust (BSMHT) PPI and he had provided some good evidence in Oct-Nov 2006 of evasion of Section 11 consultation with a concerning pattern of alteration of an MH Day Centre service by increments over time, effectively driving away some patients . These combined evidences and patterns have revealed real layers of flaws in the local practice of "modernising" policy that is desired by the Government. Dr Lynne Jones M.P. has more latterly, after meeting constituents, who have re-enforced claims of poor consultation and patient support, written to the BSMH Trust and asked them to improve their patient consultation practice and follow up, and demonstrate that more openly ..

The BSMH Trust have been very slow to respond ..

(2)

The Patient & Public Involvement Ethos And Supporting Patient's Needs More Fully

Sec of State for Health John Reid issued the words in 2003 that the Health Services should trust the patient .

"Trust me I am a patient"

(2/1)

Yet in both PPI terms and in ordinary experience terms of being a patient broadly, there has not been solid supportive cornerstones. It is not possible broadly to have more genuine democratic patient involvement rights as an MH patient until Patient Choice of treatments comes into being properly in the services that are currently overloaded with system Top-down approaches and more bureaucracies. I would urge the costs of those bureaucracies should be converted into more genuine therapy and marketised therapeutic community supports for patients as soon as possible. In one sense we need eventually less bureaucracy surrounding "Patient involvement" and more consumer demand-side democracy via Choice for the immediacy of proper patient involvement in health to take place.

(2/2)

Yet the Government has clearly seen MH as a way of socially engineering people back to work or "socially including them" yet the reality of this overapplied (by mistargetting) approach has in Birmingham, seen patients being uncoupled without choice from services despite PPI concerns. All along we the patients have seen a command and control approach both from the Govt. and the local Trust and other bureaucracies. On the PPI some of us were quickly aware that NIMHE bearing in on the services was hailed as an innovator but was changing into little more than an attempt to get people back to work before many had even had a treatment that actually fitted them towards more genuine "Patient led" recovery.

What some of us have seen is patients being sucked progressively into the "meetings culture" because both Trusts and NIMHE and other agencies have shaped "patient involvement" inside the pre-existing vacuous disempowering context of no "Patient Choice" and therefore into one of the pre-existing bureaucratic practice models i.e. : *meetings meetings meetings* is all the game ..

(2/3)

Suddenly empowerment was translated as "patients going to meetings" with planners and teams.. This is frankly and eventually frustrating and quite crazing.

First and foremost medium and longer term patients need REAL Choices of treatments which fit them , are individualised, and are therapeutically supportive post-crisis so they can become the best socially creative shape that is possible without being sucked back into crisis cycles yet again. Secondly all need development grants for their needs . They don't need meetings after meetings with planners and agencies.

Immediacy of support means Patient's Choosing their health support packages and doing so locally where it fits them .. That's real involvement .

(2/4)

Being an MH patient on the PPI was very difficult as it was for other patient-colleagues because the Commission For Patient & Public Involvement In Health would only give a carer's allowance so that someone could be alongside the patient-member at meetings . I proposed to CPPIH as Deputy Chair, a special support group in late 2004 - 2005 with the CPPIH region and said it should have some counsellors on it to help with the stress of being a PPI "mental health" member which was made additionally stressful because we were effectively monitoring our own Trust which in the main did not service the PPI mental health patient members well either . CPPIH responded to me by saying if the PPI was too

stressing they would not recommend it. LINKs I hope will support mental Health patients needs for those who get involved.

(2/5)

Whilst its true some instability is embedded in being an MH patient its clear this has to be treated as a disability factor and shored up appropriately with individual special group supports . A colleague on the PPI remarked that keen reflective knowledge by patient-members themselves, of what factors worsen intrinsic instability in the whole service context surrounding the patient, was a real asset strength of the PPI. Patient-members thus were seen to be indicators of realities . Yet poor supports by CPPIH undermined that asset strength and much of it was lost because of the additional stress on patient-members.

All new arrangements must look to the immediacy of what Patient Involvement has to mean. It has to mean patient power existing at the very GP and/or clinical gateway to services that fit them by PATIENT CHOICE .. If CHOICE is avoided then we enter the mystification of tinkering with services (the meetings culture) and creating health bureaucracies to socially engineer "results" which are mystifyingly leaving many of us unsupported therapeutically . This is not a reality you can avoid from a patient perspective . It is where many of us live inside paradoxical arrangements or services that do not support our needs and which we are trying to alter in a double paradox of monitoring them !

(3)

LINKs

LINKs (Local Involvement Networks) are proposed for a future when at least some PPI's were getting to grip with trying to democratise patient health services through statutory Section 11 Consultations. Apparently the Govt. believed the "pace of reform" was being slowed down by PPI's insistence for instance on following Section 11 consultation practices. A DOH paper indicated that. So where is the implication of patient democracy in that ? Are LINKs a woolier way of watering down perceived opposition ?

(3/1)

Where MH services are varied and that will affect health outcomes of those patients already in receipt of a service e.g. Mental Health Day Care Centres , then any consultations should be backed by law and that power should be retained. Consultation should be seen to be done individually at Centres and transparently so and must be recorded otherwise local health officials will play games with this in a bid to secure an easier flow of apparent (rather than real) policy results from their management perspective. MH patients will suffer . That is what I have already observed . The BSMHT PPI did so too in a 2005 "Impact Study" when following up patient experiences after service changes. With poor check and balance local bureaucracy dictates . The Local Trust also "buried" a PPI report from Dec 2004 to July 2006 which asked for the patient's own voice of satisfaction to be recorded. The Trust quite cynically created a staff report about patients and said that was satisfactory. Therefore there has to be a robust power to monitor this kind of service-knows-best phenomena with LINKs and it cannot be solely left to OSC's. In Birmingham the task would be too much. On the other hand without the power of "Patient Choice" in MH we will not create effective patient-shaping of mental health but only a trend to deny the patients own voice of choice more insidiously under layers of new mechanisms. Consultation and "Patient Involvement" must go hand in hand more with "Patient Choice" too - all must increasingly re-inforce the other ..

Thus LINKs must retain an independent power to view in on what is happening in service areas where patients are affected by proposed variances of services . They would be a warning system that should both have the power to view in and refer matters to the OSC or even beyond to the Health Care Commission and Sec of State .

(3/2)

The new Foundation Trusts Governor and Non Exec. member relationship with LINKs I do not think can be anything but a co-scrutiny view. But its also broadly a nonsense for MH patients to pretend "partnership" through proxies like Governors without the equalising "bottom- up" power of purchasing choice of health packages in MH, strengthened by LINKs watching over matters and being patient-orientated. Foundation Trust arrangements with LINK's have to keep looking at "bottom-up" patient led arrangements and securing their evolving reality. LINKs have to have conjoined function with all involved to secure more "Patient Choice and led" services.

Duplication of functions here are actually notionally necessary otherwise the large Trusts can escape attentions on their performances because there is not enough people to do the scrutinising . It is to be hoped that this "bureaucratisation" is an transitory evolution towards patients controlling more of their own health packages and rendering "middle mechanisms and groups" about what they want more redundant in time .

(4)

Complaints procedures

I am not convinced the Local Mental Health NHS should believe in the efficacy of its own complaint procedures which can be very conflict model driven still with MH patients in my experience . In fact there needs to be a beefed up ICAS which is accountable too to LINK's . There ought to be recourse too to independent mediation with the State paying . I would not ideally use either the Trust's complaints procedures or indeed its PALS services both of which are flawed locally and inspire no confidence at all in me . LINK's should have the simple power to have local hearings about patient problems to take evidence too . They should augment OSC function as well as have freedom to report and express themselves.

(4/1)

ICAS as it shaped for MH in my opinion in Birmingham, does not inspire confidence locally and is weak . MH Advocacy itself in Birmingham is cherry picked for easier to deal with category groups and many have overclose financial arrangements with the PCT's or Trusts. Some patients and their problems also fall through geographic catchment nets of advocacy networks so ICAS needs to be strengthened . It needs to be retained and made stronger.

(5)

LINKs Checks And Balances

A LINKs body with an MH Sub Committee arrangement for instance, will almost certainly be made up of pre-existing relationships and would need some duties in law (to ensure the patient's perspective) to balance out its inherent tendency to keep the local status quo . Reform momentum in favour of the patient must create a way to challenge that. The PPI's were notionally and somewhat Independent . The LINK's may turn into a new body where local groups with favoured arrangements will support themselves within LINKs without

deeper authentic connection to patients. Some already claim a connection patients interests that is not completely valid . We have a "User Voice" in Birmingham (from 2002) where all ex users are Trust staff now and the local PPI is set to put forward a model for its independence (after a public & patient petition expressed the need) yet its clear the Trust wanted to dilute the patient voice into this "User Voice" mechanism it could handle, and that does not produce any stats on patient's seen and solutions created .

(5/1)

Therein lies a problem of local health bureaucracy having too much power to arrange others apparent "voices" and that can feed potentially into a less than independent LINK's body .

I feel the LINK's must have the power to commission independent research therefore to performance review themselves in an honest manner - that must involve patient's views locally without mediation by Trust professionals or staff ..

LINKs should be able to create their own visiting teams to go to see patient facilities and services otherwise we weaken the notion that the services are to be viewed accountably at a direct experiential and facility level . "Hand's On" like this approaches are real to patients and will help confidence building in the process .

LINKs must have the formal power to issue reports of concerns to whomsoever . This is a democracy and the bureaucracy in health is far outweighing the ability of the ordinary patient and public to create public accountability and due criticism .

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