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The Moore Adamson Craig Partnership LLP is a specialist engagement consultancy which led the work with the MND Association on the creation of the MND Year of Care pathway commissioning tool and its transformation (along with pathways for Parkinson's and Multiple Sclerosis) to a web-based "ready reckoner" format for commissioners to access via "Neuro Navigator".

This memorandum to the Public Accounts Committee for its session on 18 January 2012, reflects MAC's views on the shortcomings around neurological commissioning and integration of services for people with neurological long term conditions which have given rise to the failures so strongly identified in the National Audit Office report *Services for People with Neurological Conditions* (December 2011).

'5 years after this NSF was published, not a single audited site could meet a single Quality Requirement'

That is the damning conclusion of the [LTNC NSF half way review](#). As far as we can see, there has been no outcry about this national failure – as there certainly would have been were the subject cancer or heart disease or diabetes as opposed to neurological conditions.

According to the evidence submitted by Neurological Commissioning Support to the Health Committee enquiry on commissioning:

Neurological Commissioning Support has discovered that there are insufficient numbers of health and social care staff with specialist training and understanding in neurology who are competent to manage the needs of the 8 million people living with a neurological condition in England (and 10 million in the UK). The lack of understanding of the needs of these people has led to excessive and costly length of stays in hospital or inappropriate emergency admission where preventative treatment would have been more cost effective as well as enhancing the individual's quality of life.

The orphan NSF

Parkinson's UK says the government has abandoned the LTNC NSF. It recently told the Health Select Committee

*.... the foundations for neurological commissioning are too weak to see health and social care services through the transitional period. **The Coalition Government have abandoned the National Service Framework for long term neurological conditions without putting in place anything to replace it.** Even with the National Service Framework in place, neurological*

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services were often not meeting the quality requirements. Without it, we worry that the services that are in place will not continue to be commissioned by GP consortia. In two or three years time, neurological services could have fallen away with little impetus to replace them.

An Opportunity Lost, maybe Forever

MAC's view from working in the field is that "Long Term Conditions" as a concept is not understood by most clinicians or commissioners to include neurological conditions. This NSF was mis-named from the start. That makes the LTNC NSF very much a "lost NSF" and the carers for people with LTNC are often "lost carers" whose needs are not even looked for, much less met.

There was never any alignment between the LTNC NSF, the commissioning guidance for LTNC of April 2007, the NSF neurological care metrics that the Healthcare Commission was developing (but never used) and the "10 Quick Wins" for local implementation. The potential synergy between these was so obvious, but was squandered and lost. Why did this happen? Because no one was in charge.

Custodians of what?

In 2008, the third sector neuro organisations were told bluntly by Government, "you are now the custodians of the NSF". Despite the sterling work of those who created this NSF, Ministers didn't own it, there was never enough sustained national level leadership and – crucially – no resources were put to achieving the "quality requirements" and metrics in it, unlike the CHD NSF.

The drive for integrated services

Integrated services reflecting individual needs and marshalling skills and resources across the health and care sectors for the right people in the right place at the right time. That's what we should have now after 60+ years of a nationally funded health service. But we don't have it and in some places things are becoming more fragmented as clinical networks break up in the post-PCT confusion of emerging clinical commissioning groups.

A recent case in point is the National Audit Office's damning inquiry into services for people with neurological conditions like MND, Parkinson's and MS identifying persistent disconnects and [failings around emergency admissions](#) despite massive investment. More money doesn't automatically mean better outcomes.

"Improving outcomes by working together"

That's one reason why the joint [Kings Fund/Nuffield Trust recommendations](#) to the Future Forum and the DH on integrated commissioning are worth attention. What they are talking about is integration of services around the needs of individuals (elderly people, children) with complex needs and many others with long term needs, including end of life care. That is all to the good but not new. It should have happened a long time ago of course. There is already a guide to this, the [National Voices Principles of Integrated Care](#) .

Social care elephant in the room

There is a big policy elephant in the room: the vexed social care resourcing issue. The report merely identifies this as a “barrier” to integration. That it certainly is. But by far the biggest barrier to integration is the acute-focused clinical culture of most of the NHS and the local authority protectiveness of much of social care. These are like oil and water and, frankly, they need nuking. Our view is that without organisational integration, common pots of money and buckets of inspirational and innovative leadership in the professions and councils, the “pace and scale” of change which the report says is vital is unlikely to happen. There are too many vested interests conspiring against it.

Patient and carer power and partnerships?

Could patients and carers not charge the barricades and demand integrated services? Individual budgets may be one way to tunnel underneath the obstructions. But it is not sufficient to talk only about personal health budgets. That is only part of the picture: we need integrated health AND care budgets for individuals – at realistic levels – as anyone with a long term condition will tell you who uses services across the sectors.

Patients and carers could leverage more power in the system in their role as budget holders. But they need brokers and guides to act as agents and facilitators with service providers if they are to maximise their purchasing power and not to get ripped off. Here is a big partnership opportunity for 3rd sector bodies and for specialist clinicians like neurological nurses - will they rise to it?

More radical thinking needed

Blockages to integration are not just about resources. It is about more subtle things, including professional leadership and personal fulfilment. Dr Peter Carter, CEO of the RCN, made this plain before the Health Committee recently: the impulse of good practice like integrated services has to be “*encrypted into the culture*”. Florence Nightingale might have said it differently, but not any better.

Until we develop more capacity in primary and community health care to deal with demand outside of hospitals, too many elderly, frail people and others with complex and long term conditions of all ages are going to end up there by default as the NAO report on neurological services shows. This is bad for them and bad for the institutions that have to receive them.

The reality of NHS provision – and it does not have to be bricks and mortar, there can be “virtual wards” in the community – has not matched the political rhetoric about this goal. All governments share the blame here and a few glib targets will not turn the situation around quickly. Just look at who is occupying a high proportion of acute beds to see what the problem is when people cannot be cared for at home or in intermediate settings which are better and safer for them. Better yet, we need to prevent a much higher proportion of unplanned admissions in the first place.

Health and care are a continuum. We must break down the funding and cultural barriers between the health and care sectors and the rivalries and turf wars between professions. To achieve integrated services, professionals must do this in partnership with patient leaders.

Outcomes are the New Targets

Coalition health policy is clear: targets are on the way out and outcomes are coming in as the new focus. There is nothing essentially wrong with that, so long as they are the right outcomes and that there are consensus standards to refer to in order to keep the new commissioners and their providers on the straight and narrow where good neurological practice is concerned. Third Sector neurological organisations are excellently placed to make sure that the Government understands the work already going forward on MND, PD and MS YOC commissioning pathways in particular and that the outputs of this work are incorporated into the new government's thinking about pathway tariffs and quality of outcomes.

Costings too low?

Our concern is that bodies sponsoring this work could suddenly find that centrally taken decisions about what is "affordable" will downplay quality and focus only on costs, and those costs will be lower – possibly very much lower – than the real costs being revealed by YOC work in long term neurological conditions. Centrally fashioned "commissioning packs" may have no user-led content in them and may not reflect the breadth and depth of health and social care inputs which appropriate year of care pathways must have.

As the pre-diagnosis 18 week pathways targets are also being removed, people with possible LTNC could face a double whammy: not getting a timely diagnosis and commencement of treatment and also not getting an appropriate care pathway in place which delivers quality outcomes that are affordable, deliverable and acceptable.

Which way now?

In the current climate of reduced resources, things could go forwards through QIPP or they could start to go backwards through removing key posts like specialist neurological nurses. One thing is clear to us: everyone concerned with long term neurological conditions needs to make sure that their voice is heard – loudly and often – and their investments in quality and effectiveness are not wasted.

Removal of performance management raises the clear danger of slipping/drifted back into long waiting lists and unresponsiveness, despite the Government's stated intention that this should not happen. The new clinical commissioners must hold providers to account for good outcomes. Many PCTs were not very good at this in the past, so why should their successors suddenly get better?

Setting a Clear Course

To address all of this, we need leadership from neurological leaders across the clinical, social care and user-led sectors, which is based on setting a clear course for commissioning at

consortium level and the role of the National Commissioning Board in terms of the division of long term neurological conditions between them. Some will be “specialised” and some won’t be – and should not be. Some will have “specialised” elements in their intervention possibilities and then there is always the question of new drugs appearing on the market to consider. Cancer drugs are getting all the running about this, but there are plenty of other conditions to consider in terms of NICE approvals and their cost benefits.

Safe Haven Needed for Neurological Commissioning

We think all of this is going to be troublesome because there is no consensus about what goes where for neurological commissioning. GPs historically do not have a strong affinity with neurological conditions and there will be temptations to let this drop off the commissioning table. What proactive line will the neurological 3rd sector community take to overcome this? “Nothing about me without me” must be owned by people with LTNC in order to switch on the power of the patient and carer voice.

As the half-way evaluation of the Long Term Neurological Conditions NSF showed, and the NAO report underscored, wherever users of neurological services are, they are certainly not “at the heart of neurology commissioning” as they ought to be. Until they are at the heart of everything that concerns them, we will not escape the chaotic situation articulated by the recent NAO report.

Dr Andrew Craig
On behalf of MAC Partnership
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