



## **Submission to the Australian Commission on Safety and Quality in Health Care on “Consumer” Engagement strategies**

**August 2008**

### **Introduction**

It is the central plank of this submission that more extensive implementation of the community controlled comprehensive primary health care model throughout the Australian health system would provide much greater institutional capacity to achieve “consumer” and community engagement with a focus on quality, safety and service responsiveness. As part of this reform, there is also the need to reform the current professional controlled primary medical care system, which does not engage consumers and the community and is not transparent or accountable about quality and safety, into a community controlled comprehensive primary health care system that is transparent and accountable about quality, safety and patient outcomes. This would assist the Commission to achieve its stated aims of:

- Engagement with consumers, patients and carers
- The right of people to be heard and involved in their care and the health system and,
- A safer, more effective and more responsive health system

In this submission, the work that Congress has been doing and the quality, safety and patient outcomes that are being achieved will be used as a case study to provide evidence that the development of more community controlled comprehensive primary health care services should be a key strategy for achieving the Commission’s aims.

The discourse using the word “consumer”, rather than patient, arose within the dominant neoliberal discourse which understands the health system as a business in a market economy. In addition, it symbolises the less politically threatening concept of atomised, individual consumers as compared with the collectivised power of people acting as a community to engage in the health system. Congress believes that the term consumer should be no longer used<sup>1</sup> because the people who utilise the health system are not economic entities consuming goods in a market place rather they are social

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<sup>1</sup> Because Congress believes the term consumer should not be used the term community is used throughout the rest of this submission in place of the term consumer.. Where the term consumer has to be used it is used in inverted commas to symbolise our concern.

beings living in communities seeking care in a health system with very large knowledge imbalances. We need to go “back to the future” and revive the language of community engagement and community control

## **Central Australian Aboriginal Congress**

Central Australian Aboriginal Congress (Congress) is an Aboriginal community controlled comprehensive primary health care service that has been in operation since 1973 in Alice Springs.

Congress provides about 50 000 patient consultations each year to a service population of 6500 permanent residents and 1800 visitors. The permanent residents are seen more than 7 times each year on average. There are eight branches including the Services Branch, the Alukura (maternal and women’s health), Male health, Social and Emotional Well Being, Education and Training, Childcare, Corporate Services and Directorate, including public health. The Services Branch is the largest branch and employs fourteen Aboriginal Health Workers, eleven nurses and more than ten general practitioners. It operates the general clinic that includes an on site pharmacy, dental and transport service. There are a range of community health programs that provide outreach services to high needs groups including an early childhood home visitation program, a chronic disease outreach program and a frail aged and disabled program. Congress has also engaged extensively in Aboriginal health policy development and health system development and has a strong focus on quality and safety.

## **A brief history of community and “consumer” engagement in the health system**

A grass roots Aboriginal movement in collaboration with non-Aboriginal activists led to the 1967 referendum<sup>2</sup> and subsequently, a new period in Aboriginal Affairs was established - the era of self-determination. Aboriginal Community Controlled Health Services developed within this context including Redfern in 1971 and Congress in 1973. In the mid 1970’s Aboriginal health services developed the first national peak body – the National Aboriginal and Islander Health Organisation or NAIHO. In 1977 NAIHO developed a *National Black Health Plan* that advocated for a coordinated and collaborative approach to the project of improving Aboriginal health. Whilst this plan was never adopted as such by governments, it was a crucial document in terms of uniting health services around a vision of better health, strengthening their input into government policies and influencing those policies. NAIHO was defunded in the mid 1980’s by Clyde Holding, Minister for Aboriginal Affairs, following extensive criticism of the new Labor government. However, NAIHO continued to function on funding from philanthropic institutions and successfully advocated for the development of Australia’s first *National Aboriginal Health Strategy* completed in 1989. In 1991 NAIHO ceased functioning to make way for the new National

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<sup>2</sup> The 1967 referendum gave Aboriginal people citizenship and the Commonwealth government constitutional power to make laws in relation to Aboriginal people, a power which it previously held only in the territories it directly administered i.e. the Northern Territory and the Australian Capital Territory

Aboriginal Community Controlled Health Organisation (NACCHO) which was established in 1992 as part of the implementation of the National Aboriginal Health Strategy. Aboriginal community controlled health services have also developed peak organisations at the state and territory level, such as the Aboriginal Medical Services Alliance of the Northern Territory (AMSANT)<sup>3</sup>. They have worked on developing the current *National Aboriginal and Torres Strait Islander Strategic Framework* and other key national frameworks that are improving the quality of the health system for Aboriginal people. The impact of Aboriginal health services advocacy (attachment 1) and the development of the Primary Health Care Access Program (attachment 2) are powerful examples of the way in which community controlled health services have enabled community engagement for a more accessible, quality and responsive health system. Without community controlled health services these reforms would not have been possible.

With the election of the Whitlam government in 1972 the first universal public health system was established through the introduction of Medibank and the Community Health Program (CHP). Under the Community Health Program block grants were provided for the establishment of community controlled health services in the poorer suburbs of the capital cities – in areas where GPs would not choose to work in sufficient numbers. These community controlled health services also engaged with local communities and were powerful advocates for a more responsive, higher quality health system. They also established effective national advocacy bodies such as the Australian Community Health Association.

Unfortunately, support for the mainstream development of community controlled health services was relatively short lived due to opposition from two main sources. State governments did not like the CHP because they felt that these services which were directly funded by the Commonwealth government were an unnecessary duplication of their role and responsibilities in providing health services. They also felt very threatened by the effective and powerful advocacy of these “independent services” on key health system issues focused on quality, safety and system responsiveness. The Australian Medical Association was also very opposed to the CHP as it did not want salaried GPs working for and managed by the community. They were concerned to protect the right to the private practice, “Fee for Service”, small business model of General practice even though it was clear at the time that this model was not as effective at delivering accessible, high quality care in a manner which was more responsive to the needs of the community – especially in the poorer suburbs where it is much harder to access a private GP. With the election of the Fraser government the CHP was gradually disbanded and, as a result, community controlled health services have largely disappeared from the mainstream health system. Although community health centres still exist in many places they by and large do not have the funding to employ salaried GPs and medical care has been divorced from community health. Organisations like Congress are left as the torch bearers of what

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<sup>3</sup> AMSANT was established after an historic three day meeting in Alice Springs in October 1994 organised by Congress. The meeting was attended by Aboriginal community controlled health services from around the Territory. The motivation for establishing AMSANT was the need for stronger Aboriginal health leadership to advocate for new administrative arrangements in Aboriginal health to improve access to better quality services and to address the broader social determinants of health. AMSANT is one of the State and Territory affiliates which together make up the national body, NACCHO

this powerful model of primary health care service delivery can do in improving the accessibility and quality of the Australian health system.

The history of community controlled health services and their peak bodies is a history of bottom up community activism for better access to quality health services and better health gain including action to address the other social determinants of health. The demise of this model of service delivery is at least in part because of the effectiveness and power of their political advocacy for a more responsive and higher quality health system and their willingness to take on powerful entrenched professional and private business interests in their pursuit of these goals. The need for governments to create “consumer” organisations, such as the Consumer Health Forum (CHF), at least partly arose because of the vacuum in community advocacy that was created by the deliberate defunding of community controlled health services and their peak bodies. Community controlled health services remain the strongest expression of community engagement in the health system and have been and still are the most powerful community advocates in the Australian health system. The creation of the CHF and even the popularisation of the discourse around the term “consumer” was much more led by a progressive health minister<sup>4</sup>, rather than through a process of community engagement and activism..

It has also been the experience of Congress that some individuals purporting to be “consumer” advocates are dismissive of the advocacy of community controlled health services claiming that these services are captured by provider concerns whereas they are more free and able to speak on behalf of “consumers” and the community more directly. This is in spite of the fact that such advocates are not accountable in any way to the people they purport to represent nor do they often have access to the type of technical advice that can inform their advocacy. There has been unnecessary tension between “consumer” organisations and community controlled health services at times and it is very important that the Commission recognise community controlled health services as legitimate “consumer” advocates but more importantly that the term community is at least always used in conjunction with the term “consumer” but, as stated earlier, Congress would prefer the term “consumer” stopped being used altogether.

It has also been the experience of Congress that organised medicine tends to focus on what the literature has called “Descriptive” representation, partly because they know that such advocacy is less effective and powerful and will not challenge the existing power relationships in the health system. Thus, doctor’s organisations are more likely to accept an individual “consumer” representative or an individual Aboriginal person rather than a representative of the community controlled health sector. Descriptive representation is where the focus is on whether an individual advocate is from a particular racial group, geographic location, gender etc. This contrasts with “Substantive” representation where the focus is on the informed content of the advocates knowledge and their accountability back to the community they purport to represent rather than the colour of their skin, gender etc. Congress believes this is an important distinction to make at times and while it is always important to try to ensure that both descriptive and substantive representation on behalf of communities is achieved it is not always possible and, if a choice has to be made, then substantive

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<sup>4</sup> Neil Blewitt in the Hawke Government

representation is the more fundamental need and will lead to better outcomes for the community.

The development of organisations like the CHF within the neoliberal ideology of people who consider themselves to be “consumers” in a market place has largely determined the type of advocacy that has occurred. It is often about ensuring greater choices for middle class “consumers” in the medical market place as well as other important issues around access and quality in areas where an adequate workforce already exists. Thus the CHF supported the private health insurance rebate in spite of the opportunity cost of not investing these public funds in the public health system and the evidence that it would lead to a less efficient and less effective health system, especially for poorer people, including Aboriginal people. There is a need for more fundamental advocacy and analysis to ensure access to quality care in areas where there are inadequate services as well as the need to promote the community controlled health service model in spite of the opposition of organised medicine. This is not to say that groups like the CHF are not needed, they play an essential role, but only to say that a stronger form of community engagement is required to make the health system more responsive and to ensure all Australians, including the most marginalised, have access to quality health care even in the most remote parts of the country.

This type of advocacy is even more urgent as it has become common for senior health department officials to speak openly and candidly about the so called “Access / Quality” trade off in rural and remote areas. As a result Aboriginal people in remote communities in the NT are forced to accept the fact that in the case of non community controlled health services managed by the Department of Health and Family services where there is no resident GP, in many cases their health services are being provided by nurses who are not properly trained or qualified, practising far outside current legal requirements. They are prescribing and ordering pathology on a regular basis in a manner which puts the safety of Aboriginal people at serious risk, especially in relation to inappropriate prescribing. Community controlled health services do not accept the so called “access / quality” trade off and have ensured that resident GPs are part of the primary health care team.

## **What are the characteristics of effective community advocacy organisations**

Effective community advocacy needs to meet the following criteria:

1. It needs to be able to mediate the relationship between community knowledge and technical, medical, public health knowledge. There is a need for an equal partnership between health professionals and community members to build powerful advocacy.
2. It needs to be accountable back to the community that it represents and,
3. It requires “Systematic or deep listening capacity”

Community controlled primary health care service meet these three criteria better than any other model of health service delivery. Firstly, they provide a vehicle for relationships between health professionals across disciplines and community members – it is this partnership between the community and professional expertise that is one

of the keys to ensuring there is greater power to their advocacy. This is a relationship in which key technical knowledge's can be demystified so that community members can gain greater insights into particular problems as well as the other way round, where community members can ensure that health professionals listen to and act on their concerns and issues. Community controlled health services are vehicles through which community members can mobilise and take action to address the key social determinants of health relevant to their own communities. Community members are able to ensure that the service is responsive to their needs and that the health system more generally is meeting their needs. They attempt to ensure that the health system focuses on the prevention of premature death and disability and health promotion and not only treatment of illness.

Community controlled health services are accountable back to their communities in many ways. The most obvious mechanism is through the Annual General Meeting where committee members are elected to govern the service and ensure it is meeting community needs in an open and accountable public meeting. In addition to this, board members are embedded in their communities and listen to the concerns raised with them on the streets, in shopping centres and in their own homes creating the organic capacity to engage with the community.

Finally, there is the concept of systematic listening capacity or deep listening. It is important that any organisation or individual purporting to speak on behalf of the community has the capacity to listen to the concerns that are in the community in a manner which is more than just about focus groups and client satisfaction surveys. This includes attending and listening to concerns expressed in community meetings, at funerals and other social gatherings, coffee shops etc. It is difficult to describe this concept but is about having community networks and relationships so that the organisation is deeply embedded in the community and really in tune with current concerns and community led solutions.

### **What is the evidence that community controlled comprehensive primary care services leads to community engagement and health system improvement**

There are a number of large scale research projects currently attempting to answer this question in a robust and systematic way. The Teasdale Corti project is one such international research collaboration which Congress is part of. In this submission Congress will use itself as a case study to provide evidence of the effectiveness of the community controlled service model on achieving community engagement and a focus on quality care and improved health. In doing this it is important to appreciate that the outcomes that Congress is achieving are primarily a function of the model of community controlled primary health care itself and not the result of a particular group of individuals working in a particular place that cannot be generalised across the Australian health system. The community controlled service model is the enabler through which health professionals can then achieve better patient outcomes including quality and safety in health care.

## **1. Congress, AMSANT and the transfer of health funding (attachment 1)**

Congress was instrumental in the creation of the Aboriginal Medical Services Alliance NT which is the peak body of all Aboriginal community controlled health services in the NT. AMSANT is an organisation which has engaged over 20 Aboriginal communities in the NT in political advocacy for major institutional changes that have improved the quality of the Aboriginal health system. The outcomes of the transfer have been described in the attached paper but more recent outcomes include:

- An increase in the OATSIH budget from \$50 million to \$550 million leading to better access to quality primary health care services
- A further increase in access to MBS and PBS
- Much better access to pharmacies and pharmacist and the medicines that are essential for good health outcomes such as statins, aspirin and ACE Inhibitors.
- The development and implementation of the National Aboriginal and Torres Strait Islander Strategic Framework

## **2. The development of the Primary Health Care Access program (attachment 2)**

Congress was instrumental in the development of this program which was built on the success of the transfer and further enhanced access to quality primary health care services for Aboriginal people. The PHCAP was in many ways a revolutionary attempt to establish a mechanism to both create and adequately fund community controlled health services and ensure better access to quality care and improved health outcomes for Aboriginal people. It has led to the implementation of a needs based, equitable weighted population health funding model which has seen much greater equity in the funding and delivery of primary health care services across the NT.

The key objectives of PHCAP (overview of the PHCAP, DoHA, November 2002) are:

1. Increased availability of appropriate primary health care services where they are currently inadequate;
2. Local health systems that better meet the needs of Aboriginal and Torres Strait Islander people; and
3. Individuals and communities that are empowered to take greater responsibility for their own health.

One of the central aspects of the PHCAP was population health funding, which was achieved and funds pooling which has only been notionally achieved. Unlike the Aboriginal Coordinated Care Trials actual funds pooling has not occurred due to the opposition of state and territory governments and the lack of willingness of the Australian government to force the issue. The result is some Aboriginal communities with 2 or 3 separate providers who are unable to work together to ensure quality health care. Communities need greater capacity, through the establishment of community controlled health services, to engage in these key policy decisions and ensure that the Commonwealth state buck passing, so characteristic of Australian

Federalism and Aboriginal health, is not allowed to continue to seriously undermine the quality of health care.

### **3. Health Workforce and distributive justice (attachment 3)**

Congress and AMSANT have been relatively lonely voices continually raising one of the most critical issues for improving the quality of health care in Australia – equitable access to health professionals. It is here that it is imperative that the health system has organisations that are not controlled by the health professionals themselves so that these types of policy issues can be raised. Many Aboriginal people in remote parts of the NT only have access to nurses who are not qualified for the work they are doing. They prescribe and order pathology even though this is not legal and they are not registered nurse practitioners. This has gone on for many years and is a major quality care issue but the response from government is that people living in remote areas, including Aboriginal people, have to accept that there is an “Access / Quality” trade off. This is a concept that needs to be removed from the minds of health policy makers and replaced with a vision of equitable access to quality health care for all. It is possible to ensure that GPs are accessible everywhere through the use of both financial and non financial incentives. It is primarily community controlled health services that are advocating for the types of regulatory mechanisms, such as geographic provider numbers, that are needed to really make a difference. It is only through informed community engagement that these types of quality health system issues are going to be addressed and the Australian health system needs to increase the institutional capacity for this to occur.

### **4. Aboriginal health framework agreements and community engagement in health policy making**

Under the Framework Agreements in Aboriginal health state and territory governments were required to establish Aboriginal health planning forums which are the principal advisory structures to governments on Aboriginal health policy. The framework agreements require states and territory governments to resource AMSANT and the other state peak bodies to be able to effectively participate in health policy making. These structures have enabled greater community engagement in key health policy decisions and such arrangements would not have been possible without the community controlled health sector. It is important to note that ATSIC, which used to be part of the joint planning process, was unable to effectively advocate on health policy issues because it did not have the necessary expertise on health issues even though it was an organisation governed by the community. The advocacy of the community controlled health sector is much more substantive because it is informed by professional and community knowledge in a partnership.

### **5. Quality improvement and clinical governance at Congress (attachment's 4, 5 and 6)**

Congress has developed an extensive quality improvement system and collects and analyses data on a range of key performance indicators which enable the organisation,

which includes the community, to know whether quality care is being delivered and whether key outputs and outcomes are being achieved.

Attachments 4 and 5 are PowerPoint presentations to the first national conference on Quality Improvement in Aboriginal health *Budgery Booroodi* (Sydney 2007) and these outline the extent and breadth of the systems Congress has put in place to ensure quality improvement and good clinical governance. This information is fed back to the community through the elected health committee twice a year. All health professionals participate in the quality improvement system that includes file auditing and monitoring of patient flow and waiting times and other key indicators. Such systems either do not exist or are very rare in non community controlled primary medical care services which are effectively not accountable to their communities for the quality of care they provide.

Congress participated in the National Primary Care Collaborative (NPCC) and was able to demonstrate much better outcomes at baseline on the key indicators. This is true for many other community controlled health services that participated. For example, at baseline 30% of all diabetic patients at Congress (n=746) had a total cholesterol less than 4 compared with 16% in a select group of leading general practices. Over 80% of all coronary heart disease (CHD) patients (n=146) were on Aspirin compared with about 50% for mainstream general practice. Blood pressure control was much better for both our diabetic and CHD patients. Why is it that Congress and other community controlled health services are achieving better outcomes on these types of clinical indicators than mainstream general practice and therefore providing better quality care?

These some of the factors likely to be important:

- Effective community engagement and a community driven imperative to provide quality care, reduce waiting times and improve health
- Salaried health professionals who are able to spend more time with patients i.e. 30minute appointments
- Effective feedback to health professionals and peer review processes on quality
- Management, public health and other key support staff who ensure effective policies, procedures and systems
- No economic, cultural or physical barriers to access including free health care and medicines, transport services and exceptional GP workforce retention

These factors are part of the community controlled health service model and cannot be created through the Fee for Service private practice model as further explained in a paper delivered by Congress to the Australian Primary Health Care Research Institute Workshop on Primary Health Care reform, Canberra, 2005: *Aboriginal Community Controlled Comprehensive Primary Health Care: better access, better service provision and greater health gain per dollar?* (Attachment 6).

## **6. CARPA Evidence based medicine and programs**

Congress was instrumental in the development of the CARPA standard treatment manual which has played a major role in ensuring that all health professionals follow evidence based guidelines in their clinical practice. It is a policy requirement to follow

CARPA at Congress unless a reason is documented as to why this is not appropriate and all practitioners are audited against the use of these guidelines. This provides good protection to patients from inappropriate prescribing and other treatment.

A further important aspect to this protection is that Congress from its inception has banned representatives of Pharmaceutical companies from coming onto its premises and talking with any of its health professionals during work hours. This policy decision was years ahead of its time as strong research evidence about the negative impact of academic detailing on quality prescribing has only emerged in more recent years. Congress ensures that its GPs and other health professionals receive appropriate inservice training that is completely independent of the influence of the pharmaceutical industry and this is critical to reinforcing the commitment to using evidence based guidelines such as CARPA.

#### **7. Advocacy on the performance of the hospital system (attachment 7)**

Congress and other community controlled health services have continually advocated for improvements in the quality of care in hospitals. This is done through letters of complaint on serious problems in terms of access to specialist care (eg attachment 7: all names removed) as well as editorials and articles in peer reviewed journals raising key health system issues such as the delay in cancer diagnosis and treatment for public patients, especially in rural and remote areas, leading to worse survival outcomes compared with privately insured patients (Boffa, J. 2008 Cancer Care for Indigenous Australians (Editorial) *Medical Journal of Australia*, May 19, 188 (10): 560-561). This complaint has led to very significant system changes which will ensure that all men with PSA's greater than 20 are made category one patients and therefore should not have to wait more than a maximum of 2 months for a biopsy even without private health insurance.

Congress has been advocating for key sentinel indicators to monitor access to tertiary care for conditions such as CHD, renal disease and diabetes for many years. Congress has also participated in many coronial inquests and provided information to the courts that has assisted to highlight major system problems with the health system that has then led to system improvements. This includes the need for mortality review processes in Northern Territory public hospitals that have only commenced in recent years. Congress, and other community controlled health service play this role regularly and the contribution this makes to the improvement in the quality of the hospital system does not get recognised. It is again a contribution that community controlled health services can make effectively because of the independent nature of these organisations even though they are part of an interdependent health system

#### **8. The integration of Alcohol and other drugs and mental health services with primary health care**

No only has there been a separation between medical care and community health services as mentioned earlier but these services are further separated from alcohol and other drug and mental health services which are in turn separated from each other. Instead of providing holistic, multidisciplinary care to whole persons the primary care system tends to provide fragmented, single discipline care. This has created problems such as "Dual Diagnosis" which is a creation of the health system and not the fault of

the many patients who have co-existent alcohol and other drug and mental health problems. Congress has provide many submission over the years to reviews of the mental health system advocating for a re-integration of these service with primary health care and has recently led the development within AMSANT of the attached policy paper on these issues (attachment 8). In addition, Congress has developed a social health team of psychologists, social workers, Aboriginal Family Support workers and others. Congress has also been successful in wining a competitive research grant to ascertain the effectiveness of alcohol and other drug treatment services within a comprehensive primary health care service (attachment 9) All of these developments are aimed and demonstrating that better quality care responsive to the holistic needs of patients can be provided within a comprehensive primary health care service rather than by multiple, fragmented, single discipline providers. Patients with multiple problems do not want to be buck passed between providers who have become so narrowly focused that they cannot treat the whole person. This again is a key feature of community controlled comprehensive primary health care services which is not being achieved by other primary care service models

## **Conclusion**

Community controlled comprehensive primary health care services are the most effective way to ensure that there is both effective “consumer” and community engagement in the Australian health system and a much stronger focus on quality, safety, service responsiveness and health outcomes. The Australian Commission on Safety and Quality in Health Care needs to adopt a policy that supports the planned development of community controlled comprehensive primary health care services throughout the Australian health system as one of the major mechanisms to improve safety, quality and consumer and community engagement. This will require the Primary Health Care Access Program, or a similar program, to become a mainstream initiative based on needs based population health funding and the capacity to employ health professionals across disciplines who can spend more time with patients. Such a program would also need to ensure that there is the capacity to foster the development of community controlled health boards with specific funding for community capacity building such as occurred in the NT Aboriginal Coordinated Care Trials.

It is not sufficient to place individual “consumer” advocates on to committees, boards and other structures as a means of ensuring effective community engagement and advocacy. While this approach is better than nothing it too often leads to descriptive rather than substantive representation with advocates who do not have access to the necessary supports to inform their advocacy and who are not accountable back to any particular community. This type of representation is also more likely to lead to advocacy for greater individual choice and power within the existing health system rather than the more fundamental reforms that are need to improve quality, safety and patient outcomes. It can at times be quite tokenistic.