Flinders University
Southgate Institute
for Health, Society
& Equity

Aboriginal health in Aboriginal hands

Community-controlled Comprehensive Primary Health Care @ Central Australian Aboriginal Congress

What this report is about . . .

Comprehensive primary health care (PHC)—which focuses on the whole patient, not simply a disease state—has been the **global 'gold standard'** for addressing community health problems since the 1970s, including in Australia. Ideals are rarely put to the test, however.

In 2010 the National Health and Medical Research Centre (NH&MRC) funded the **Southgate Institute for Health, Society and Equity at Flinders University** to investigate how well community health services in South Australia are conforming to the principles of comprehensive PHC and the reasons for their success or otherwise.

Six community health services were selected for **intensive study** over several years: 5 in South Australia and 1 in Alice Springs in the Northern Territory.

Of these six, the **Central Australian Aboriginal Congress** ('Congress') in Alice Springs **best embodied the principles of comprehensive PHC**—by a long way.

This is a **remarkable achievement** for an organisation that started in 1973 with nothing, struggled to keep funded in the bureaucratic ghetto of Aboriginal affairs for its first 20 years of operation, and only in 1996 was certified to receive support through federal- and state-level funding mechanisms (i.e., Medicare), like other Australian health services.

Congress has had to fight every step of the way in the most challenging circumstances this country has to offer, but they have succeeded. Although there is still far to go, this is an Australian story worth telling.

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CONGRESS IS . . .

A community-controlled health service that provides **culturally respectful comprehensive PHC** to **Aboriginal people** living in or near **Alice Springs**, or visiting the town from much farther afield.

Today, Congress is one of the most experienced Aboriginal PHC services in the country, a strong political advocate of closing the gap in Aboriginal health disadvantage and a national leader in improving health outcomes for all Aboriginal people.

SOUTHGATE INSTITUTE IS . . .

An internationally renowned research centre, located in the School of Medicine at the **Flinders University** of South Australia, which is concerned with the **social, economic, political and equity aspects of public health** policy, planning and implementation. Professor Fran Baum, the institute's director, served on the Committee on Social Determinants of Health of the United Nations' World Health Organization (WHO), whose 2008 report set global standards.

An Australian story worth celebrating

MESSAGE FROM FRAN BAUM, AO

Over my career in public health which started in the mid-1980s I have researched community health centres and become an admirer of the ways in which they have been able to put the principles of the WHO's Alma Ata Declaration on comprehensive primary health care into action. I have had the opportunity to observe primary health care in many settings around the world and it is evident that **Congress is an extraordinary model of good practice.**

The Aboriginal Community-Controlled health service model pre-dated Alma Ata and was one of the social movements which contributed to the original 1972 Whitlam Community Health Program. This has been the only time that community health has been at the front and centre of national policy on primary health care.

The genius of the Aboriginal community controlled model is that it is able to take the best of a strong medical model of care and combine it with a social health model. As a Commissioner on the Commission on the Social Determinants of Health I saw the accumulated evidence that good community health care has to be based on an understanding of and appropriate action on the social and cultural determinants of health. Congress stands out as an Australian service that has managed to do exactly this.

People's health is profoundly affected by the political and economic structures shaping their everyday lives. Opportunities for leading a healthy and flourishing life are affected by racism, the distribution of income, wealth and employment and educational opportunities. While a health service can't change those things they can take account of their impact on individual's lives and play a crucial lobbying role. They can also act to redress injustice and health inequities through their style of service provision.

Congress is a community-controlled model of comprehensive primary health care that needs to be acknowledged and celebrated. This report summarises the research evidence which my team at the Southgate Institute is pleased to have produced in partnership with Congress staff. We are very grateful for their trust in allowing us to conduct this research and congratulate the Board, community and staff on their fine commitment to a truly comprehensive primary health care service. We would also like to acknowledge the National Health and Medical Research Council for funding the research (project grant 535041), and the research team who worked on the study, and who are listed on the inside back cover.

We hope the report highlights what makes Congress and other community controlled health services like it special. **My vision is that every community in Australia would benefit from having such a service.** National policy makers should pay close attention to its benefits and achievements.

Fran Baum, AO
Director, Southgate Institute

Forty years of achievement

MESSAGE FROM DONNA AH CHEE

It's been over 40 years since Congress first opened the clinic on Hartley Street. **All the old people who fought for this service, who worked so hard in the face of so much opposition to make this possible, would probably find it hard to believe how far we've come.** Not because they doubted what our people could do, but because the social and political climate was so aggressively opposed to what they were trying to do. A lot has changed. Not enough, mind you, but a lot.

Congress is now a $40 million operation, with more than 300 staff who provide more than 160 000 episodes of care each year to about 12,000 Aboriginal people living in Alice Springs and in six remote community clinics in Central Australia.

In addition to this, the clinics service over 4,000 visitors each year. One of the best indicators of the success of this comprehensive PHC approach is the improvement that has occurred in the health of children. **When Congress started infant mortality rates were around 170 deaths per 1,000 live births and now they are around 12.** Our babies are no longer dying from easily preventable causes and the challenge has moved to the promotion of health development. Since 2001, there has also been about a 30% decline in all cause mortality for Aboriginal people in the NT.

We have been able to achieve this because **right from the start Congress was based on PHC principles** and understood the need to address both access to quality, multidisciplinary sick care and the social determinants of health, because the conditions of Aboriginal life clearly have a huge impact on Aboriginal health.

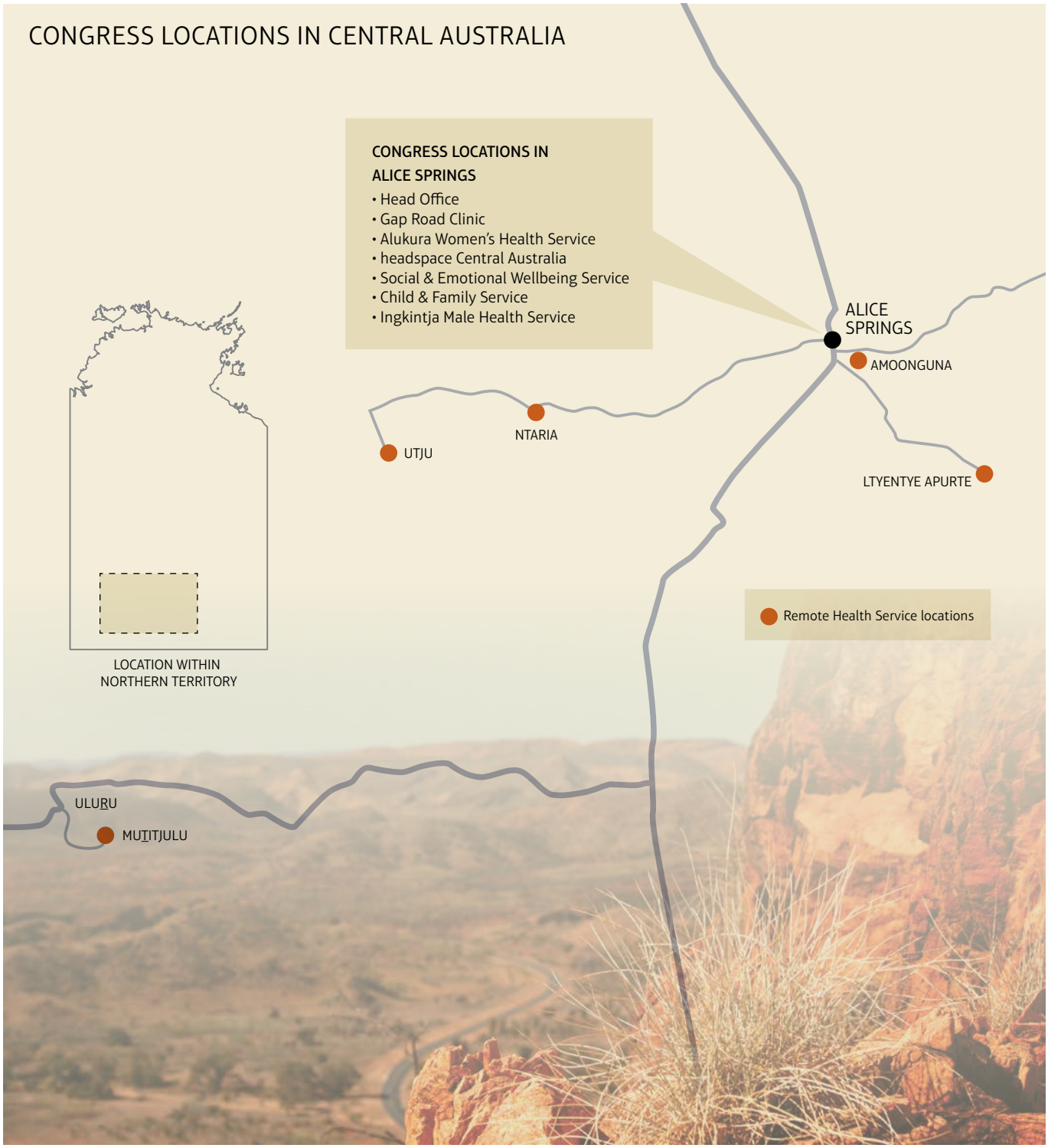
Aboriginal people are the most over-researched group in the country, but this research conducted by Southgate Institute for Health, Society and Equity was important to us. Increasingly, research is becoming our ally in the struggle to improve health as it is being done in accordance with the strategic priorities of organisations like Congress. **Congress's policies and practices have always been evidence-based.** Congress is appreciative of the collaboration with the Southgate Institute which has helped to demonstrate so clearly what Congress is doing right.

I hope by reading this report both Aboriginal health and the critical role that community controlled comprehensive PHC plays in health improvement will be better understood.

Donna Ah Chee
CEO, Congress

A big catchment

It's impossible to appreciate Congress's achievements in delivering primary health care without understanding how large and varied its catchment area is. Alice Springs and the network of town camps in and around the municipality, constitute the core. Aboriginal people live both in the town and in the town camps. However, the catchment also includes remote Aboriginal communities—from the Mutitjulu community at Uluru (Ayers Rock) in the south to, Utju (Areyonga), Ntaria and Wallace Rockhole communities in the west and Ltyentye Apurte (Santa Teresa) and Amoonguna communities in the east—among which Aboriginal people move and live. Finally, Aboriginal people from other regions passing through Alice Springs also use Congress's services.



What's inside . . .

For Congress it has always been both treating sick people and making them well.

From its very inception Congress embodied the core primary health care principle of both treating sick people and making them well through multidisciplinary sick care while at the same time addressing the underlying socio-economic determinants of ill health. For Congress it has always been 'both/and' and not 'either/or'.

In the beginning it was about providing emergency shelter through a tent program, creating an accessible bank that enabled enrolment for vital transfer payments following the referendum granting citizenship as well as running a clinical service with GPs and the first Aboriginal Health Workers. Now, Congress sees approximately 10,000 urban clients each year, providing about 130,000 unique episodes of care (see Figures 1 and 2). Congress has continued to combine the provision of essential clinical services with action on the broader social determinants of health. The key points of this report are:

- Congress arguably represents the **Australian 'gold standard'** for community-controlled comprehensive PHC that conscientiously addresses social determinants in everything it does, as it is able.
- 90% of staff interviewed by the Southgate Institute said they take the social determinants of health into account **in the course of their work**.
- Nearly all staff surveyed (96%) reported **collaborating with other organisations** in the course of their work during the previous year, including (in order of proportion of contacts) hospitals, community health services, NGOs, Centrelink, schools, police, housing services, local government/councils, the education department, other PHC services, the NT Medicare Local, private allied health, private GPs, professional associations, tertiary education institutions, divisions of general practice—even the media.
- The vast majority of Congress clients rated the **quality of care** at Congress high or very high.
- In the diabetes case study, clients with type 2 diabetes were **'enthusiastically positive about the care they received'**, and demonstrated good levels of glycaemic control and blood pressure.
- Congress has helped Aboriginal people in other areas of the country to establish their own **culturally appropriate health services**.
- The Southgate Institute study concluded that, of the six health services investigated over five years, Congress **'provides a model'** for building into an organisation's governing structure the means for community participation in decision-making and service planning.

. . . key points

Figure 1. Congress unique urban clients (service area and visitors), by year

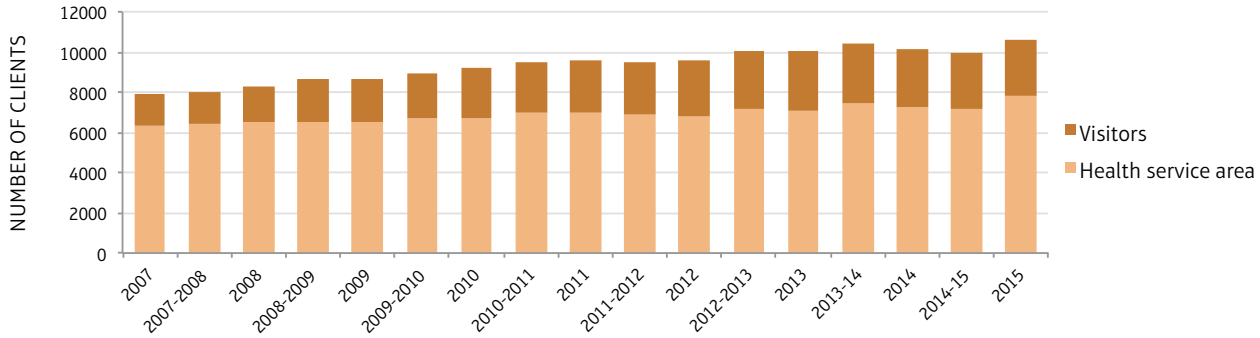
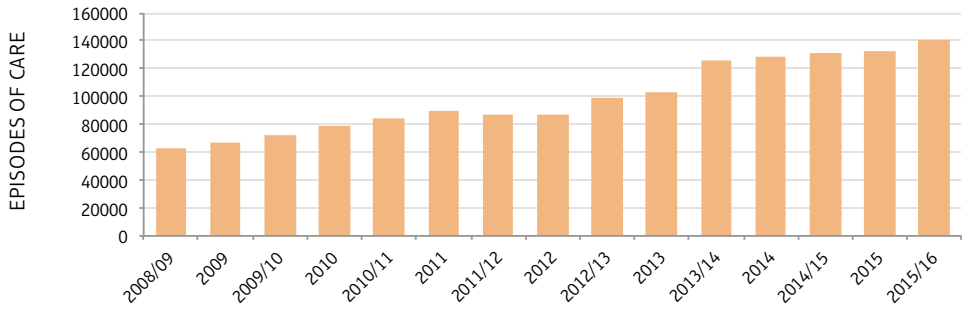


Figure 2. All Congress urban episodes of care, by year



Primary health care . . .

The primary health care (PHC) movement began in the early 1970s out of concern to correct massive social and economic inequalities between rich and poor countries, and between rich and poor communities within countries.

As a social justice-based community development movement gained pace worldwide, it became clear that inequalities in illness and mortality rates result from personal context within communities characterised by social, economic and political inequality, factors. That means some communities and groups have much less chance for a healthy life than others.

This is especially so among colonised Aboriginal and Torres Strait Islander peoples. Traditional health services are ill-equipped to address these social determinants.

ALMA ATA DECLARATION

The **historical reference point for comprehensive PHC** is the manifesto issued on 12 September 1978 at the end of a major international conference in Kazakhstan hosted by the World Health Organization (WHO).

How PHC differs from traditional health care is easily understood in terms of **'before' and 'after'** the Alma Ata Declaration, which:

- Articulated a **new definition of health**.
- Established health and access to health care as a **human right**.
- Included **social, economic and political factors** among those contributing to poor health, meaning that solutions require a **multi-sectoral approach,** including the recognition that there was a need for 'a new economic paradigm' in order to achieve 'Health for All'**.**
- Put **responsibility on national governments** for providing equal access to health care, and **developing the health workforce** to meet greater demand.
- Advocated **community participation** in health care planning and implementation.

More selective variants of PHC have been introduced since, but the Alma Ata Declaration remains the benchmark for comprehensive PHC.

Table 3. Conceptions of health care before and after the 1978 Alma Ata Declaration on Primary Health Care

	BEFORE PHC	AFTER PHC
Definition of health	Hard to define. Generally, the absence of disease or infirmity.	'A state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity . . . ' (Drawing on the 1947 WHO Constitution)
Focus of treatment	Symptoms of disorders or diseases exhibited in a patient.	A multifaceted individual who is unwell and is embedded in a context that may or may not support heath.
Status of health care	Public or privately funded services to which individuals may or may not have access.	Health is a socio-economic issue, and access to health care is a human right.
Approach	Curative, rehabilitative.	Health promotion, disease prevention, curative, rehabilitative.
Temporal duration	Short-lived intervention.	' . . . ongoing process of improving people's lives . . . '
Socio-economic factors	Negligible.	Critical.
Government's role	Variable.	Responsible for ensuring all citizens have equal access to health care.
Health care policy	Variable.	National policies are required.
Sectors involved in health care	Health and medicine.	Health and medicine, education, food supply and nutrition, water supply and sanitation, housing, family support and family planning, transport, public works, communication.
Role of the community	Negligible.	' . . . People have the right and duty to participate individually and collectively in the planning and implementation of their health care.'

. . . a global paradigm shift still gaining ground

PHC IN AUSTRALIA

The principles of PHC began to be formalised in Australia at a Monash University conference in 1972. The meeting, ***Better Health for Aborigines***, was convened by Basil Hetzel, inaugural professor of social and preventive medicine at Monash; Yami Lester, a Yankunytjatjara man; and Jim Downing, a Uniting Church minister. The **first** Aboriginal community controlled health service, Redfern Aboriginal Medical Service, had been set up in 1971.

The topic was how to address **shocking Aboriginal morbidity and mortality rates, often referred to as 'third world'**. The principles of PHC appeared to be the only way to approach health problems linked with such widespread disadvantage.

In 1973 the National Hospital and Health Services Commission introduced a **community health initiative incorporating PHC principles**. Although short-lived, the program led to the incorporation of PHC principles in Australian health policy and accreditation criteria and a funding stream for community controlled health services. The Aboriginal community-controlled health sector of which Congress is an exemplar, continued to develop and grow. All of this took place before the Alma Ata declaration in 1978.

Runs on the board

'A PHC approach is the most efficient and cost-effective way to organise a health system. International evidence overwhelmingly demonstrates that health systems oriented towards primary health care produce better outcomes, at lower costs, and with higher user satisfaction.'

— MARGARET CHAN, DIRECTOR-GENERAL, WORLD HEALTH ORGANIZATION (2007)

Evidence for the effectiveness of PHC has been collected three times for the Australian government in the past 15 years: the National Centre for Epidemiology and Population Health (NCEPH) 'Legge Report' 1992, the 'Griew Report' (2008) and *Better Health Care* (2001). All three reports conclude that comprehensive PHC is the only strategy for addressing the overwhelming health problems faced by Aboriginal people with a realistic prospect of success. Some observations:

- The main conclusion of the NCEPH report was that if the Australian health system was re-oriented in accordance with the principles of primary health care that this would lead to greater health improvement.
- 'International experience has shown that a comprehensive approach to primary health care can contribute to **significant improvements in health in developing countries** and **among Indigenous populations** in developed countries comparable to Australia.' *(BHC, p. 11)*
- 'Evidence from the [USA] and New Zealand suggest that primary health care has **contributed to narrowing the life expectancy gap between Indigenous and non-Indigenous peoples** in those countries . . . [and] that **poorer access** to primary health care is associated with a **widening** life expectancy gap.' *(Griew, p. 7)*
- '**Improvements in Aboriginal and Torres Strait Islander infant mortality rates** are consistent with better access to primary health care services'—although they remain 'almost three times greater than for other Australians, and significantly worse than for those for Indigenous peoples overseas.' *(Griew, p. 7)*
- 'Changes in disease mortality patterns—including the **shift from mortality due to infectious diseases to mortality due to chronic conditions**'—are well-documented, especially in the Northern Territory, 'and are **plausibly related** to the development and actions of primary health care services.' *(Griew, p. 7)*

Social determinants of health . . .

'Our children have dramatically different life chances depending on where they were born . . . In countries at all levels of income, health and illness follow a social gradient: the lower the socioeconomic position, the worse the health.

'It does not have to be this way, and it is not right that it should be like this. Where systematic differences in health are . . . avoidable by reasonable action they are, quite simply, unfair.'

—*CLOSING THE GAP IN A GENERATION*, WHO COMMISSION ON THE SOCIAL DETERMINANTS OF HEALTH (2008)

HEALTH BEYOND THE INDIVIDUAL

Every person who seeks help from Congress—or any health service—is embedded in a **context of daily life** that has **multiple layers**, all of which affect health. The first layer involves immediate or **'proximate' factors** known to impact health, many of which would be checked in most medical settings. (See diagram above.)

However, these proximate factors are embedded in a **larger social, economic and political context** that powerfully shapes the patient's lived reality as well, including health. If these environmental factors are not addressed, they will continue to adversely affect health.

Considerable lip service is paid to PHC principles in health policy discussions and drafting, but in reality most health services worldwide run on a traditional **'medical model'**, – primary medical care – which is designed to treat defined conditions according to certain therapeutic protocols. The medical model places **responsibility for health** squarely in **individual behaviour** (e.g., smoking, drinking, overeating, not exercising enough, following a doctor's orders).

While PHC principles recognise the impact on health of factors beyond the control of the individual—e.g. housing, family, education, income, culture, the availability of transport—it is increasingly recognised that health is not simply socially *affected* but **socially determined.**

How a society is **structured politically**, what sort of **economic system** it has, and how these two work together with **culture** to distribute not only **public and private goods** but also **public and private goodwill**—praise or blame, acceptance or discrimination—also have a profound impact on health, **affecting different populations in different ways**.

. . . context (really, really) matters

Generally speaking, people living in poverty, lacking education opportunity, and disadvantaged ethnic minorities that tend to be both, tend also to have the **worst health** in a society. In part due to the body's automatic response to psychological stressors, there is a cost to health paid by people **lower on the socioeconomic gradient** that is not incurred by people higher up.

Aboriginal people remain the most socioeconomically disadvantaged Australians.

RIO DECLARATION (2011)

Under the auspices of the World Health Organization (WHO), the **Commission on Social Determinants of Health** (SDH) collected and analysed global evidence for the impact of SDH on health, and the health inequities arising from them.

In a 247-page report entitled *Closing the Gap in a Generation* published in 2008, the Commission concluded: **'Social injustice is killing people on a grand scale.'** Doing something about it should be an 'ethical imperative' worldwide.

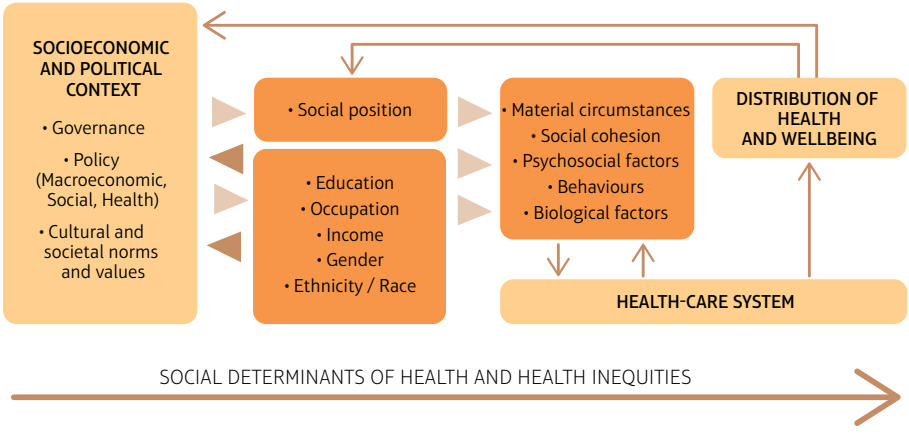
The Commission made 3 over-arching **recommendations**, which provided the backbone of the 2011 'Rio Declaration' on SDH produced by a world conference held in Brazil to discuss the findings.

1) **Improve daily living conditions**. Especially concerning the wellbeing of girls and women; early childhood development; education; and the conditions in which people live and work.

2) **Tackle the inequitable distribution** of power, money and resources in the way society is organised, which produce inequities in the social and material conditions of life.

3) **Measure and understand the problem**, and assess the impact of action. This includes making SDH a greater focus of public health research.

WHO COMMISSION MODEL OF HOW SDH AFFECT POPULATION HEALTH



Source: *Closing the Gap in a Generation* (2008)

SDH A PRIORITY @CONGRESS

- **Website** clearly sets out Congress's commitment to SDH. See: **http://www.caac.org.au/aboriginal-health/social-determinants-of-health/**
- 90% of staff interviewed by Southgate Institute said they take SDH into account **in the course of their work**.
- 59% of staff said SDH are taken into account in Congress **service planning**.
- 67% of staff interviewed thought SDH are on the Congress **policy agenda**.
- Examples include Congress's advocacy on alcohol supply through the People's Alcohol Action Coalition, a preschool readiness program, a Men's shed that provides job skill training, and collaboration with the housing authority on housing issues.
- Congress has long prioritised and carried out **research** to ensure its approach to health care is based on scientific evidence, a key recommendation of the WHO Commission.

'Put simply, the social gradient in terms of housing, education, employment, access to justice and empowerment are directly linked to the disastrous health outcomes we face.'

—*REBUILDING FAMILY LIFE* (CONGRESS)

Congress in context . . .

Congress became a pioneer of comprehensive PHC out of necessity, not ideology.

Addressing the social determinants of health was the most rational response to the circumstances when Congress was created, not simply because it coincided with a worldwide movement.

Today, Congress arguably represents the Australian 'gold standard' for community-controlled comprehensive PHC that conscientiously addresses social determinants in everything it does, as it is able.

Congress is one of two organisations created at an **historic meeting** of Aboriginal people from many language groups on 9 June 1973 in Alice Springs.

The **Central Australian Aboriginal Legal Aid Service** (CAALAS) was established first to help Aboriginal people with the legal troubles, and personal trauma, that flowed from life in a social, economic and political system alien to their culture, which had taken their land, herded them onto missions and reserves, and was designed, in many respects, to control their lives. **Congress was the second**.

Just as the Congress Party founded by Mahatma Gandhi gave voice to Indians' determination to be free from Great Britain, so Congress was established to be **'the voice of Aboriginal people in Central Australia'**—for a 'fair go' in every other area of extreme disadvantage that blighted Aboriginal life.

This included being forced to use health, education and social services that were insensitive —if not downright hostile— to Aboriginal needs. The Alice Springs Hospital was desegregated only four years earlier.

It also meant that, right from the beginning, Congress was charged with **looking after more than just Aboriginal health**. Health was just one piece in a multi-dimensional picture of deprivation.

FOUNDING PRINCIPLES

Congress was founded on several principles that set it on a collision course with government policy. At the time, policies **discriminated between 'traditional' and 'town' Aboriginal people** on the basis of how much so-called 'Aboriginal blood' an individual possessed. Instead, the meeting declared, Congress would operate according to the following ideas:

- Town and bush are **one mob**.
- Anyone who **identifies as an Aboriginal person** *is* **an Aboriginal person**.
- **Culture must be respected** in all facets of Congress's operation and service.
- **Community control** is **non-negotiable.**

. . . zero to comprehensive in 40 years

STARTING WITH NOTHING

Congress had a mandate to tackle a wide range of problems, but no resources. This meant asking for help. **Intersectoral collaboration** thus became another standard of Congress's operations.

The winter Congress was established was very wet, and many Aboriginal people had no shelter. The **'Tent Program'** was Congress's first venture, with the help of the Alice Springs Town Council and charities like Anglicare. This was clear and urgent way in which social and economic factors were affecting health.

A **'pick-up service'** was also established to get drinkers out of public spaces before they were charged with public drunkenness, a difficulty faced by the minority of Aboriginal people who drank alcohol as pubs had 'dress codes' to keep them out.

Monash University graduate Dr Trevor Cutter arrived in 1974 to **consult with people and advise** on the establishment of a community health program. Cutter was well-versed in the principles of the **emerging PHC movement**, outlined at a ground-breaking workshop at Monash as the best hope for improving the shockingly poor state of Aboriginal health.

Based on his wide-ranging consultations and PHC principles, Cutter drafted a funding submission to establish a community health program as part of the new established organisation which, together with the existing non clinical programs would create a new **Aboriginal-controlled health service** in Alice Springs. Both NT and Commonwealth health departments **opposed the application**.

FROM HARTLEY STREET (TOP) TO LEICHHARDT TERRACE

Congress in context . . .

'[By] worrying about the people, that's how Congress got so strong . . . [O]h, it just amazed me how we used to get these other new programs goin' . . . with no dollars, no dollars, absolutely no dollars.'

— MARGARET LIDDLE, SENIOR WELFARE WORKER (1970s)

'BETTER HEALTH FOR ABORIGINES'

Despite this opposition, Congress officially opened its clinic in dedicated premises on **10 October 1975** in a converted house on Hartley Street.

Employment and training of **Aboriginal Health Workers**, to work as 'cultural brokers' alongside the doctor, was an early Congress innovation, as was a focus on **staff development**, to train Aboriginal people to take over administrative jobs.

In addition to the health clinic, Congress operated a **'welfare section'**, which initially helped people apply for benefits, held the cheques of those with no postal address, and ran a bank, as well as running the pick-up service.

Over the years the welfare section grew to **encompass most of the social determinants of health**, including expanding access to housing, education (school busing), nutrition (school lunches, food vouchers), employment (via CentreLink), transport, family support, childcare, disabled and aged services, dental services, remote outreach, and alcohol rehabilitation—even assisting with organising funerals.

According to a history of the period, Congress recorded about 4,000 medical consultations its first year. The next year the number of contacts for all services more than doubled to 9,750. **Within a decade,** the number had grown to 28,000 medical consultations, 1,200 dental consultations and 25,000 welfare services—**'approximately 190 people per working day'.**

It took two decades of dogged advocacy, but in 1995 Congress finally joined the relatively **secure funding stream** of mainstream health services, including access to Medicare (1996) and the Pharmaceutical Benefits Scheme (1998).

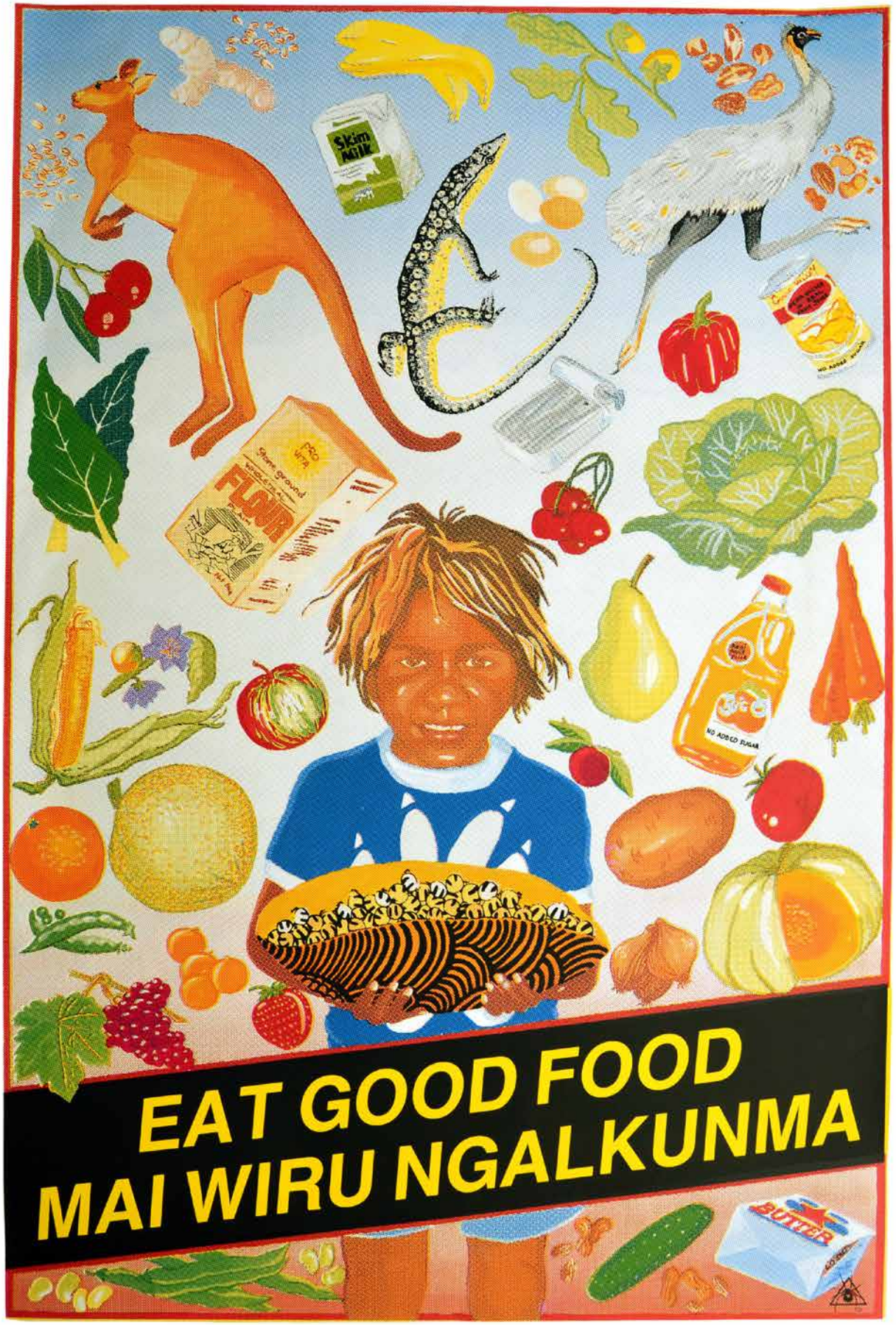
A PURPOSE-BUILT MODEL

Today Congress occupies a purpose-built facility on Gap Road, from which it has operated since 1988 and to which have been added two adjacent blocks of land and another block 5 kilometres away, as **programs and demand have expanded**.

During the Southgate study period (2009–2014), the number of **individual Congress clients grew 15%,** from roughly 8,600 to 10,000. Each client may be seen **many times per year**. Congress clients managing chronic diseases may attend the clinic up to four times per month.

From its earliest days, Congress became a **model of comprehensive PHC** for Aboriginal communities seeking to establish their own health services, from the Anangu Pitjantjatjara–Yakunytjatjara (APY) Lands to Broome. Congress today directly supports **regional health services** at Amoonguna, Uluru (Mutitjulu), Areyonga / Utju, Hermannsburg (Ntaria) and Santa Teresa (Ltyentye Apurte).

The remainder of this report shows how—and how well—Congress meets its continuing mission to deliver comprehensive PHC to Aboriginal people in Central Australia.



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What we do . . .

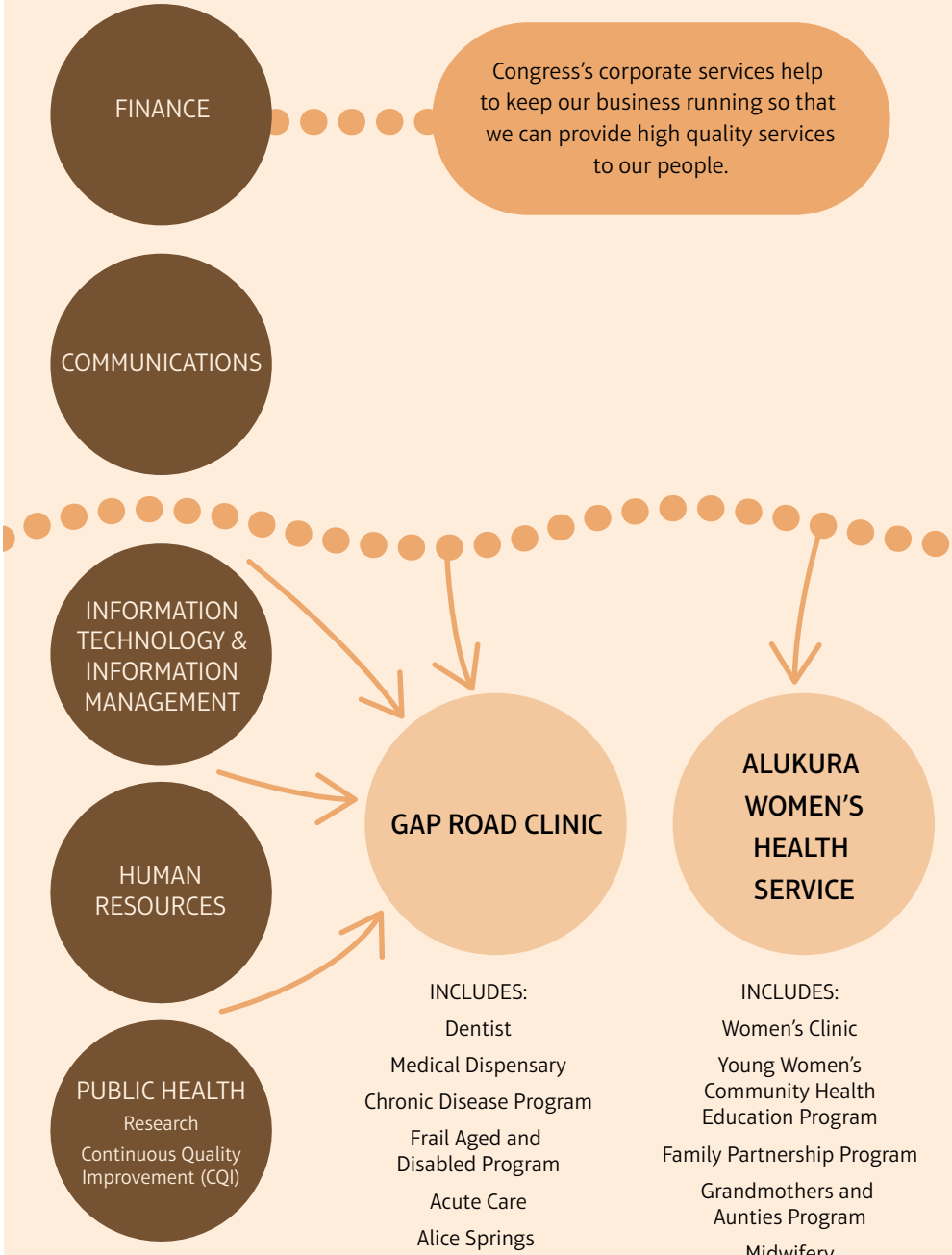
Congress has over 40 years' experience providing comprehensive primary health care for Aboriginal people in Central Australia.

Our services target the social, emotional, cultural and physical wellbeing of Aboriginal people.

THE CONGRESS VISION:

All Central Australians enjoy the same level of health

OUR CORPORATE SERVICES



. . . activities and programs

OUR GOVERNANCE STRUCTURE

Congress is an Aboriginal community-controlled primary health care service. This means that we have a membership of community members who help us to keep informed about the needs of our people.

CONGRESS MEMBERS

Congress's Board of Directors is comprised of six member and three non-member directors. The member directors are elected by Congress members and the non-member directors are appointed by the member directors for their specialised skill in important areas of governance.

CONGRESS BOARD OF DIRECTORS

CEO

EXECUTIVE OFFICE

OUR CLIENT SERVICES

INGKINTJA MALE HEALTH SERVICE

INCLUDES:

Male Clinic

Men's Shed

Young Men's Community Health Education Program

Violence Intervention Program

CHILD & FAMILY SERVICE

INCLUDES:

Healthy Kids Clinic

Childcare

Pre-school Readiness Program

Intensive Family Support Program

Targeted Family Support Program

SOCIAL & EMOTIONAL WELLBEING SERVICE

INCLUDES:

headspace (youth)

Cultural and Social Support Program

Therapeutic Program

REMOTE HEALTH SERVICES

INCLUDES:

Amoonguna Health Service

Ntaria Health Service

Mutitjulu Health Service

Mpwelarre Health Centre

Utju Health Service

EDUCATION & TRAINING SERVICE

INCLUDES:

Aboriginal Health Practitioner (AHP) Training Traineeships

Multidisciplinary teamwork . . .

'Staff are willing to listen and they help by putting you in touch with other places and services or programs available at Congress.'

—CONGRESS CLIENT

'I find with Congress that they have access to a lot more here than elsewhere that I've been.'

—CONGRESS CLIENT

ENSURING QUALITY CARE

As part of their evaluation of six primary health care services, Southgate Institute researchers surveyed 59 members of Congress staff. Of those surveyed:

- 91.5% rated **multidisciplinary teamwork**—having several health experts with different skills and expertise consulting on individual clients' cases—as the main mechanism for providing high quality care. (See diabetes case study opposite.)
- 81% said quality care was ensured by **explaining all the treatment and lifestyle options** and letting clients make the best decisions for themselves, a practice reflected in clients' evaluations of the service.
- Nearly all staff surveyed (96%) reported **collaborating with other organisations** in the course of their work during the previous year, including (in order of proportion of contacts) hospitals, community health services, NGOs, Centrelink,

SERVICE QUALITIES: MEETING A HIGH STANDARD

Southgate identified several qualities comprehensive PHC services should have besides the ideals of **efficiency** and **effectiveness** shared by all health services.

- **Holistic**. Treat the whole patient, not just disease symptoms.
- **Mix of treatment, prevention & promotion**. Community conditions and common behaviour leading to ill health also must be targeted.
- **Used by those most in need**. The most powerless tend to be those with the greatest health needs.
- **Increases individual control.** Client rights are clearly articulated. Individuals better understand factors that affect health.
- **Responsive to the local community**. Through governance and other means.
- **Supports and empowers the community**. Seeing change as a result of having input in turn changes attitudes.
- **Culturally respectful.** Affects service use and treatment.

On a 5-point scale, Congress's **clients ranked their service very highly** (between 4 and 5) on six of the nine factors.

. . . key to quality care & client satisfaction

schools, police, housing services, local government / councils, the education department, other PHC services, the NT Medicare Local, private allied health, private GPs, professional associations, tertiary education institutions and divisions of general practice.

- Over 90% said that they personally take the **social determinants of health into account** in developing treatment plans for clients to a great (67%) or moderate (23.5%) extent, and over half (51.2%) said this was accomplished both through collaboration with other organisations and advocacy.

HIGH CLIENT RATINGS

As Southgate Institute researchers found, Congress clients tend to have a high opinion of the service. Of 82 Congress clients surveyed:

- 35% rated Congress 5 out of 5 for the **overall quality** of services provided, while 48% gave a rating of 4 out of 5.
- 72.5% said that **staff explain procedures, tests and results** all of the time (37.5%) or often (35%).
- 77% said they were **provided with the information they needed** all the time (51%) or often (27%). Only 3.7% said they got the information they needed rarely or never.
- Nearly 3 out of 4 clients (74%) said Congress staff **listened to and respected their preferences** often (46%) or all of the time (28%).
- Over half of respondents (54%) said they received help from Congress staff with **issues not directly related to a health complaint**—e.g. transport, access to benefits, housing, legal matters, job training and childcare—while 32% said they received such help with **more than one issue**.

CASE STUDY: DIABETES

Chronic diseases present the greatest societal burden in terms of health funding, patient suffering and cost to the economy, and in recent years their treatment has taken priority in national health policy. As part of their study, the Southgate Institute looked at how each of the six health services handled these complex cases.

Congress saw 884 clients with diabetes in 2014–15, equating to a 14% prevalence in the service's catchment population. Researchers received permission from 30 diabetic clients to review their cases, of which 12 clients agreed to be interviewed. According to the Southgate report, in comparison with the other services Congress:

'[E]mployed the **widest range of disciplines** and arranged for visiting professionals, allowing Congress to act much closer to a **one-stop shop** for clients with diabetes compared to the South Australian services.'

- **Saw clients four times as often** (on average 4 times a month, compared to once monthly for the SA services), and monitored cases more closely.
- Enlisted the **greatest number of professions** in case management: 'all clients saw at least 3 professions . . . with the majority (70%) seeing more than 5 professions.' Of these, the most common seen were GP, pharmacist, diabetes nurse, podiatrist, and optometrist.
- Took the most **comprehensive approach to accessibility**, 'with the provision of transport, Aboriginal Liaison Officers, phone support to clients, home visitation and outreach, including Nephrocare for clients on dialysis.'
- Was more likely to **refer clients to external health services** for diagnostic tests.

Moreover, clients were **'enthusiastically positive about the care they received'** and described Congress workers 'as 'understanding', 'helpful', 'extremely informative', 'extremely friendly', 'very compassionate', 'very professional in their attitude', and 'very thorough'.' Clients also said workers gave 'clear messages' and were 'supportive'.

Congress's health centre report for 2015 shows the clinical benefits of this care for clients. About a third of the 1207 Congress clients with diabetes (32%) had good glycaemic control (HbA1c ≤ 7%), which was equivalent to the Northern Territory average for Aboriginal PHC, and 25% had high blood sugar levels (HbA1c ≥ 10%) which is less than the NT average. This glycaemic control is important in preventing cardiovascular, eye, and other complications from diabetes, including amputations. 54% of these diabetic clients also had good blood pressure control (< 130 / 80) and this is also important in the primary prevention of heart disease and stroke. Outcome data such as this was not collected in the other services in the study.

Finally, Congress helped to develop a video-based resource called **The Diabetes Story**, which is aimed at clients with low medical literacy levels and comprehension of written material and is available in three Central Australian Aboriginal languages as well as English.

How we do it . . .

'Having the evidence is not enough; knowing what 'best practice' is [is] not adequate. The best of ideas, the best of our knowledge, must come from a well-grounded base within our communities . . . [T]he evidence says that community control has superior outcomes in primary health care than solutions imposed from elsewhere.'

—*REBUILDING FAMILY LIFE* (2011)

COMMUNITY CONTROL: HOW IT WORKS

Congress was created by a community, for a community, and has remained **community-controlled for over 40 years**, often against powerful odds. Community participation, one of the key characteristics of PHC, has long been acknowledged as the source of Congress's strength.

Every person over 18 years of age in the Congress catchment area who identifies and is recognised by the community as an Aboriginal person is eligible to become a **member of Congress**. Membership is required to **vote in elections** for Congress's governing board. The Congress website explicitly encourages membership, which is free, and provides everything necessary to apply.

Every year the membership elects 3 **Aboriginal members to the board** of 6 members that governs Congress. The six community board members **then recruit and appoint 3 specialist members**, who may be non-Aboriginal people, represent disciplines relevant to Congress's activities: primary health care, finance, and governance and administration.

The board, together with the CEO and specialist members, meet every 6 weeks. After every meeting, the board **issues a communiqué** summarizing the items discussed and decisions made, which is distributed to all members and is available to all staff on the intranet.

In addition, **community members can raise issues** through board members or Congress staff.

HELPING OTHERS TO HELP THEMSELVES

As one of the earliest community-controlled PHC health services, Congress has helped Aboriginal people in other areas of the country to **establish their own culturally appropriate health services**.

1973	Central Australian Aboriginal Congress, Alice Springs
1977	Angarappa – later Urapuntja Health Service, Utopia
1977	Pitjantjatjara Homelands Health Service – later (1984) Nganampa Health Council, SA
1978–82	Lyappa Congress, Papunya
1978	Broome Aboriginal Medical Service (BRAMS)
1982	Kalano – later (1990) Wurli Wurlinjang Health Service, Katherine
1983	Pintupi Homelands Health Service, Kintore
1983	Ngaanyatjarra Health Service (WA)
1985	Anyinginyi Congress Aboriginal Corporation, Tennant Creek
1986	Imanpa Health Service
1986	Mutitjulu Health Service, Uluru
2000	Ltyentye Apurte Community Government Council Health Centre, Santa Theresa
2002	Western Aranda Aboriginal Health Corporation
2003	Utju Health Service (Areyonga)
2003	North Barkly Health Board (becoming part of Anyinginyi)
2003	WYN Health Board (handed back to the NT DoH)

'[L]ook, we as a people in this community know that if we have an issue with Congress . . . we feel like we could go and tell them. It's not a place that you've got to keep an arm's length away.'

CHR—CONGRESS CLIENT

. . . governance & community participation

ADDRESSING THE SOCIAL DETERMINANTS THROUGH TRAINING AND EMPLOYING ABORIGINAL PEOPLE

One of the important ways Congress addresses social determinants is through training and employing Aboriginal people. As of December 2015, Congress employed 309 staff in full-time, part-time, and casual roles. Of these a total of 144 staff were Aboriginal (47%). The table below shows the Aboriginal staffing level by division and by salary level.

Division	Aboriginal	Non-Aboriginal	Total
Executive / Public Health	15 (60%)	10 (40%)	25
Business Services	7 (33%)	14 (66%)	21
HR	4 (50%)	4 (50%)	8
Health Services	118 (46%)	137 (54%)	255
Salary level			
Level 1–2: Entry level roles	21 (78%)	6 (22%)	27
Level 3–5: Technical officer roles, Childcare, AHPs and admin levels	64 (81%)	15 (19%)	79
Level 6–7: Front line supervisors, experienced admin levels, new graduates RN	46 (73%)	17 (27%)	63
Level 8 and above: Management roles, GPs, tertiary qualified roles, allied health staff, experienced RNs	13 (9%)	127 (91%)	140
TOTAL	**144 (47%)**	**165 (53%)**	**309**

The reduced proportion of Aboriginal staff at the highest salary levels highlights the challenges faced by a service like Congress in employing Aboriginal people at the higher professional levels given **the continuing failure to close the gap in early childhood education and school education** to ensure there are sufficient Aboriginal people qualified at these levels. There are jobs within a PHC service like Congress that require tertiary qualifications yet there are not enough Aboriginal people qualified for these types of positions. This is where the Congress traineeships, cadetships and study support initiatives are important, as this is **a pathway to assist Aboriginal people into tertiary level studies** so that Congress can employ them in the better paid roles.

SOUTHGATE STUDY: CONGRESS IS A MODEL

The Southgate Institute study concluded that, of the six health services investigated over five years, Congress **'provides a model'** for building into an organisation's governing structure the means for community participation in decision-making and service planning—**not just for Aboriginal people** but for community-based health services more generally.

Researchers found that health services run by **non-governmental organisations** have **'more mechanisms for accountability to the community'**—for example, through boards of management—than state-managed PHC providers.

While community participation is **mandated in state-managed PHC services**, researchers found that it was **'less noticeable in practice,'** and actual opportunities for community participation had contracted.

Community participation in state-managed PHC services was **'generally limited to individual feedback on specific programs,'** for example, on a particular consultation or as part of a program's means of assessment.

Advocacy . . .

Advocacy is an important characteristic of primary health care that addresses the social determinants of health, but it usually is not a primary characteristic of most health services. In Congress's case, advocacy was its first mission—to be 'the voice of Aboriginal people in Central Australia'—and advocacy has permeated its activities ever since.

MAKING THE VOICE HEARD

By assuming responsibility for ensuring the health of Central Australian Aboriginal people, Congress necessarily took on the task of **promoting Aboriginal people's interests in many areas** not traditionally associated with health.

For example, the **Tent Program**, initiated soon after Congress was established in 1973 during a very wet winter, immediately involved the organisation in the lack of appropriate housing for Aboriginal people in and around Alice Springs as well as the **lack of secure tenure over land** on which to build such housing.

Because Congress started with nothing, **from the beginning advocacy meant collaborating** to bring about a positive result. In the Tent Program, for example, Congress got help from what is now Anglicare and the Alice Springs Town Council.

Shepherding applications for welfare payments through relevant departments and organising receipt of cheques for distribution also forced Congress staff right from the start to develop **productive relationships with public servants** in many areas.

Today, collaboration with other professionals and organisations is Congress's principal way of fulfilling its mission.

HOW IT WORKS

Individual advocacy means accessing the services needed, clinical and social, to bring the whole patient back to health, not simply to treat the symptoms of a disorder. This may involve liaison with other doctors or the hospital, social services, employment agencies, educational institutions, and organising transport. It also means following up with patients to ensure they have what they need to attend appointments.

In fact, **96% of Congress staff** interviewed by the Southgate Institute reported collaborating with other organisations in the course of their work.

Community advocacy addresses the social determinants of health through support of land rights, adequate housing and infrastructure, transport, education, and employment opportunities, in addition to community-based health promotion campaigns, for example, against smoking and domestic violence.

. . . collaborating to makes good things happen

Government advocacy takes place at the local, territory, and federal level and is often aimed at policy and funding. Congress has enjoyed great success in this area, long acknowledged by governments and peers. **The most important victory was bringing funding arrangements for Aboriginal health services under the Commonwealth department responsible for health.** This massive shift, in 1995, brought Congress's clinical activities under Medicare and the pharmaceutical benefits scheme (like mainstream services), and provided a level of funding security unknown in Congress's first 20 years.

VITAL ROLE OF RESEARCH

Research is now internationally acknowledged as indispensable for providing a **solid empirical basis for health practice and assessing the effects** of interventions. It is also necessary to provide evidence for advocacy. Congress was and continues to be a pioneer in this area as well, mainly because it had to be.

When the first Congress clinic opened in 1975, it followed a new approach to health care—through comprehensive PHC that addresses the social determinants of health. **Little research had been done in Australia** relative to this new model, and nothing in relation to Aboriginal people, so Congress took responsibility for ensuring a scientific evidence base existed for its innovations and practices.

As a result, qualitative and quantitative **research has always been an integral part of Congress's activities**, which is relatively rare among health care services Australia-wide. The current research register outlining all of the projects that Congress is engaged in is publicly available through the Congress website.

PEOPLE'S ALCOHOL ACTION COALITION: TURNING DOWN THE TAP

'Congress could never have done this on our own . . . I am quite confident that we wouldn't have got where we are now on the issue of alcohol and getting the tap turned down if it wasn't for the collaborative nature of the work . . . '

— CONGRESS STAFF MEMBER

Statistics show that Aboriginal people are **more likely than non-Aboriginal people to abstain** from drinking alcohol, but Aboriginal people who do drink are more likely to drink to harmful levels.

Where it is a major feature **alcohol affects every facet** of Aboriginal family and community life—from nutrition, employment and educational performance to levels of violence, the condition of housing stock and health. This is why one of the first programs Congress established was a pick-up service, to get drinkers out of harm's way and prevent their arrest.

In Central Australia the history of Aboriginal attempts to address alcohol misuse has been marked by **hopeful starts, dashed hopes and renewed effort**. In 1995 a group was formed of concerned individuals and organisations long-experienced in dealing with the harmful effects of alcohol. This group ultimately became the People's Alcohol Action Coalition (PAAC).

In addition to concerned community members, the PAAC includes official representatives from Congress, the Central Land Council, Aboriginal Medical Services Alliance Northern Territory, Northern Territory Council of Social Services, Central Australian Youth Linkup Service, Ngaanyatjarra, Pitjantjatjara and Yankunytjatjara (NPY) Women's Council, Uniting Church, Public Health Association of Australia NT, Mental Health Association of Central Australia, local church groups and trade unions.

The focus of PAAC's actions has been to **restrict alcohol availability** via lobbying of the NT Liquor Commission to introduce measures such as restricting trading hours, reducing the number (or opposing the expansion) of liquor outlets, increasing taxes on particularly harmful classes of alcoholic drinks (e.g., alcopops, flagons or cartons of cheap wine), reducing taxes on less harmful classes (e.g., beer), and registers of banned drinkers at taverns, pubs, hotels and takeaway liquor outlets.

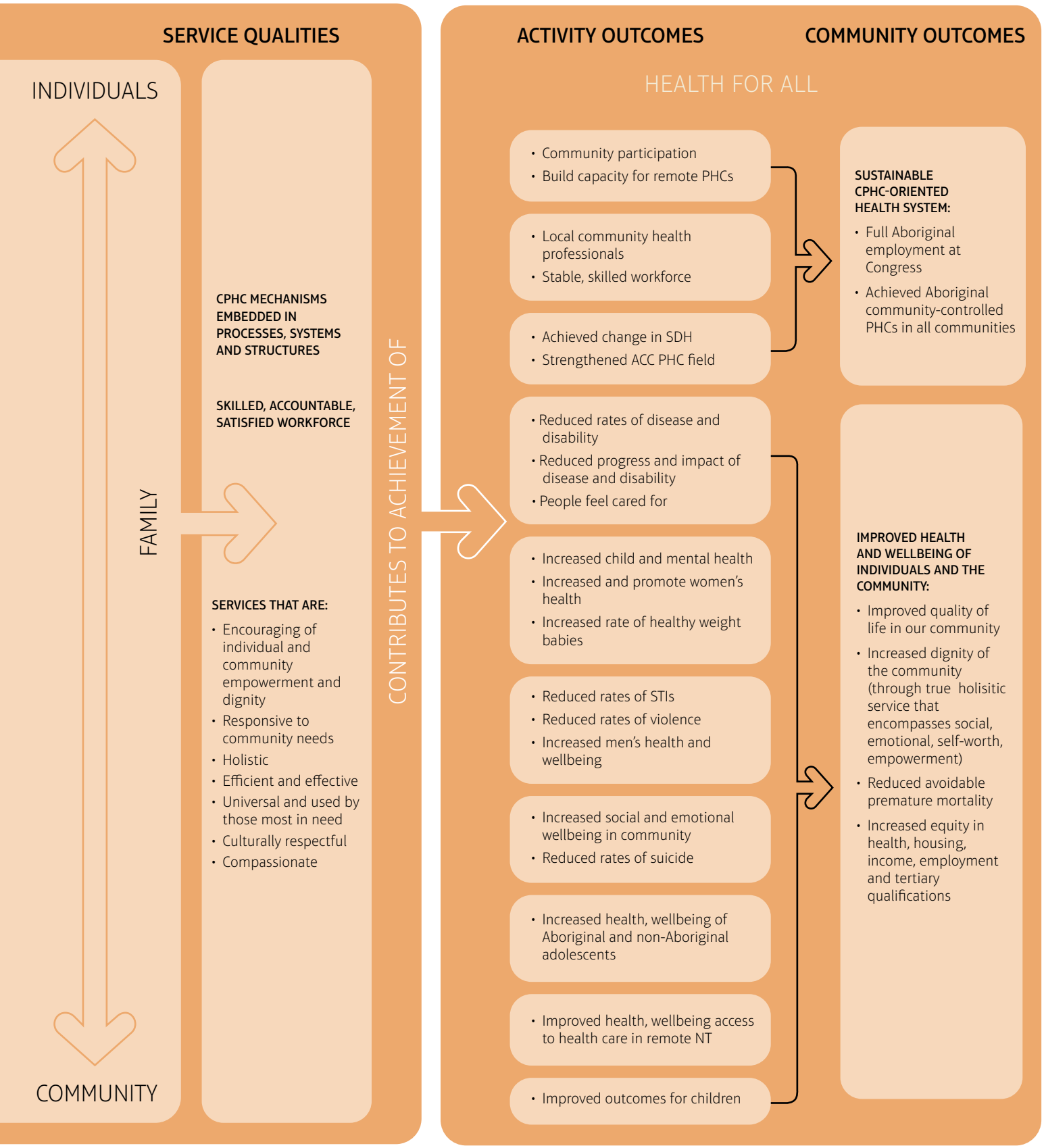
One of the strongest, most consistent research findings concerning **alcohol consumption** is its **sensitivity to price and availability**. When prices are lower, consumption is higher. When prices are higher, consumption declines. When availability is greater, consumption is greater. This is the case worldwide.

Under the slogan *Turning down the tap to bring down the harm*, PAAC has had some big wins and some losses but since 2006 there has been a 28% decline in per capita alcohol consumption (NT Government, 2015). The PAAC website (**http://www.paac.org.au**) provides the latest news on these continuing efforts.

SOUTHGATE MODEL FOR COMPREHENSIVE PHC: CENTRAL AUSTRALIAN ABORIGINAL CONGRESS

The Southgate Institute developed this program logic model to capture the ways in which a health service (in this case, Congress) works, the context in which services are provided, and their intended outcomes. Elements of the environmental context can help or limit a service's ability to enact the principles of comprehensive PHC, which in turn shape the activities the service engages in, the qualities the service achieves, and thus the community health outcomes that are the organisation's goals.

. . . putting it all together



This program logic model was developed in collaboration with the South Australian Community Health Research Unit (Flinders University) as part of the Comprehensive Primary Health Care in Local Communities project funded by the NH&MRC. For more information please visit **http://bit.ly/CPHCproject**

Ensuring the future

'More than 200 years of institutionalised dispossession, racism and discrimination have left Aboriginal and Torres Strait Islander people with the lowest levels of education, the highest levels of unemployment, the poorest health and the most appalling housing conditions.'

— OXFAM AUSTRALIA

For the first half of its life, Congress operated in an atmosphere of continual uncertainty regarding funding for its programs. The second half has been much more secure, but challenges always exist , in particular to:

- **expand programs** to address the social determinants of health.
- **conduct research** to ground programs and practices scientifically.
- preserve an atmosphere of **cultural respect**.

Although all are important, preserving the atmosphere of cultural respect that makes Congress a safe place for Aboriginal people to attend is not only vital but also the **most likely to be challenged** in the future, as governments look for ways to cut health budgets or to competitively tender out services primarily on the basis of cost rather than respect for community control.

If they don't feel comfortable Aboriginal people won't attend a clinic, doctor's office or hospital until the problem is very serious, and Aboriginal and Torres Strait Islander mortality and morbidity statistics remain a **national scandal**.

Aboriginal and Torres Strait Islander people **die 10–17 years younger** than non-Aboriginal Australians (ABS, 2011). By contrast, in the USA, Canada and New Zealand Indigenous people have a life expectancy only 7 years shorter, according to Oxfam Australia.

Moreover, a tendency exists for Australian policy-makers to make program and funding decisions based on research from abroad, which often does not reflect the needs of Aboriginal people and the conditions of Aboriginal life.

OLYMPIAN CATHY FREEMAN VISITS CONGRESS, 2012.

Low levels of **education and employment** also present barriers. Compared to 73% of non-Aboriginal Australians aged 15–64, only 44% of Aboriginal and Torres Strait Islander people have attained **Year 12 or Certificate level II** or above (ABS, 2013). Just over half (56%) of Aboriginal and Torres Strait Islander people in that age group are in the **labour force**, compared to 76% of non-Aboriginal Australians (ABS, 2013).

So long as **racism** continues to blight Aboriginal life, Aboriginal **living conditions** remain significantly deprived relative to the non-Aboriginal population, and Aboriginal health remains **a national embarrassment**, so long will there be a critical need for Congress and other Aboriginal community controlled health services.

'You can have people on what's a really expensive maintenance health program, that requires a high level of commitment to a healthy lifestyle . . . [and] you've got people who are homeless, or living in very overcrowded situations, with no ability to control their diet or fluid intake . . . and [these] are the key factors [determining whether] you do well on that program or not.'

— STAFF MEMBER, CONGRESS

Want to know more? Check it out . . .

WEBSITES

http://www.caac.org.au

http://www.flinders.edu.au/medicine/sites/southgate/

http://www.who.int/social_determinants/en/

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And by consulting the project website:
http://www.flinders.edu.au/medicine/sites/southgate/research/primary-health-care-and-community-services/cphc/cphc_home.cfm

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HOW TO CITE THIS REPORT:

Pamela Lyon (2016). 'Aboriginal health in Aboriginal hands: Community-controlled comprehensive primary health care @ Central Australian Aboriginal Congress.' Alice Springs. Central Australian Aboriginal Congress.

DESIGN AND PRODUCTION:
Bruderlin MacLean Publishing Services