

Koori Action Research in Community Health

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Introduction

This paper will tell the story of the Central Coast Aboriginal Health Action Group, how it was set up, what we have achieved and how we combine research with action to improve community health. The Central Coast of New South Wales is a mainly urban region to the north of the Sydney metropolitan area. Aboriginal and Torres Strait Islander people reoccupied the area after the genocide of the Darkinjung people. An Aboriginal Health Action Group was set up in 1993 to promote the development of Aboriginal health services, and to undertake participatory action research in collaboration with the School of Community Health at The University of Sydney.

The Health Action Group includes representatives of local Aboriginal organisations, University researchers, and indigenous and non-indigenous community members. It has provided advice to the local health authorities on problems of access to health services. worked on a profile of the Aboriginal community, liaised with professional associations, provided a forum for Koori voices and undertaken other actions. The Health Action Group works to do research in a Koori way, guided by Koori principles and informed by indigenous knowledge. This process brings indigenous and Western knowledge together, under the control of indigenous people.

Terminology

The indigenous people of the Central Coast were Kooris of the Darkinjung, Guringai and Awabakal tribes. The current population includes indigenous people from all parts of Australia, including Kooris, Murris, Nungas and Torres Strait Islanders. In this paper 'Aboriginal people' and 'Koori' include indigenous people from all parts of Australia.

Central Coast of NSW

The New South Wales Central Coast Region is located between Sydney and Newcastle, on the East coast of Australia. The region covers an area of 1,854 square kilometres, bounded by the Hawkesbury River in the south, Lake Macquarie in the north, the Pacific Ocean to the east and the Judge Dowling Ranges on the west.

According to Aboriginal tradition this region was created by Daramulen, the sky god who is the source of all power, and who now lives above the sky (Swain 1993: 127, Vinnicombe 1980). Many of the natural features, including the rivers and lakes, were shaped by the Rainbow Serpent, who rests in the swamp at Freeman's Waterholes (Needham 1981: 69).

Although the exact position of tribal boundaries before European invasion is not clear, most of the Central Coast was the country of the Darkinjung tribe. Their neighbours were: the Guringai people, whose country included the shores of Broken Bay and extended south to Sydney Harbour; the Awabakal tribe, who lived around Lake Macquarie in the north; and the Darkinjung tribe to the west, whose territory stretched behind the Judge Dowling Range, from near the upper Hawkesbury River in the south, and north to the Wollombi Valley in the north (Needham 1981: 4).

The Darkinjung lived by fishing, gathering bush foods and hunting. The region was part of an extensive trade network, and large ceremonies were held at times of the year when fish were plentiful. Ourimbah, in the middle of the Central Coast region, was a ceremonial ground in which boys were initiated. (Vinnicombe 1980)

The European invasion of Australia started at Sydney in 1788. Its effects were soon felt in Darkinjung country. Smallpox, measles and other exotic diseases quickly reduced the population (Stinson 1979: 11). Before the invasion there may have been 1,500 Kooris in 12 family groups living between Hawkesbury River and Lake Macquarie. A census of the Aboriginal population of the region in 1827 estimated a total of 65 persons, in five family groups. It has been reported that the last Darkinjung person died in 1874.

After the dispossession of Aboriginal people from their land, Aborigines and White Australians tended to live separately in space (Coombs 1994: 70). Though there were a few people who may have been descendants of the original inhabitants living near Mangrove Mountain (Vinnicombe 1980). The Central Coast region grew rapidly as a centre of European population. I have found little evidence of an Aboriginal population in the region during the post-war assimilation policy, in the 1950s and 1960s. In 1968 a local historian commented that 'these friendly and worthy people ... are no longer with us' (Bennett 1968: 3)

In the last decade the region has experienced a population boom. In the five years 1986 to 1991 the average annual growth was 4%, while Sydney was growing at 1% per year (Hunter Valley Research Foundation 1993: 4). Most of this growth is due to young families moving into the region, as high rents and house prices make living in Sydney too expensive. Some of the young families moving into the region have been Aboriginal and Torres Strait Islander people, whose

traditional country may be anywhere in Australia. Most of the present day Koori population of the Central Coast has therefore migrated into the area after a non-Aboriginal population was well established, and few of the adult Aboriginal people now living on the Central Coast were born there.

Aboriginal Health History

Prior to 1788 Darkinjung country provided an abundance of sea and land food, supporting a healthy population who gathered for seasonal events, and visited regularly with neighbouring tribes for trade, ritual and social interaction. Reports made by early European visitors indicate a vigorous and healthy population with few infectious diseases. Accidental injuries from camp fires were quite frequent, and a number of people carried the scars of spearing from tribal punishment. Local traditional medicine men, called Koradji, used herbal and spiritual treatments for these injuries.

One local historian estimated the largest native population of the region was about 360 (Bennett 1968: 3). Recent scholarship however increases estimates of the pre-invasion population in NSW four or five times (Butlin 1993: 136), giving a minimum pre-invasion population of 1,500. When Captain Phillip landed at Sydney in 1788, soldiers, sailors and convicts introduced new contagious diseases which quickly spread to the Central Coast region with devastating outcomes. The small pox epidemic of 1789 was so virulent that whole families were wiped out so quickly that they were unable to bury their dead. Contagious diseases like smallpox, measles, pneumonia and tuberculosis reduced the population of the Central Coast from more than 1,500 to a couple of hundred even before the first occupation of the region by Whites (Bennett 1968). From about 1820 the region was invaded, first by smugglers and moonshiners who set up camps along the Hawkesbury river, and then by timber getters, boat builders and pastoralists, who added gonorrhoea, and murder to the causes of Aboriginal deaths. In six years, between 1821 and 1827, the Darkinjung population was reduced from 200 to 65. A second smallpox epidemic in about 1828 almost completely destroyed the local population. In 1874 Billy Fawcner, said to be the last remaining Darkinjung, drowned in Tuggerah Lake, which had been the source of life for his people (Stinson 1979).

In short, the Darkinjung tribe of more than 1,500 people seems to have been completely wiped out by introduced diseases and deliberate slaughter in the space of eighty-six years. If there are any surviving descendants we do not know of them.

For a century after Billy Fawcner's death in 1875 there were very few Aboriginal people living on the Central Coast, and we have no information about their health status.

The last twenty years have seen an increasing rate of immigration of Aboriginal and Torres Strait Islander people into the region, and it is probable that the number of Aboriginal people now living in the region is larger than before the European invasion. The health status is quite different.

Illness Profile

There is strong evidence that the health status of Aboriginal people in the Central Coast is much worse than that of non-Aboriginal people.

The average life expectancy for Aboriginal men is about 19 years less than for the general population, and for women about 16 years less. On the Central Coast the proportion of the total population over 65 years is 17%, but only 3% of Kooris are over 65 years (Goolagong and Liddle 1994: 11, 7). The fact that the proportion of Aboriginal people over 65 is one sixth that of the general population of the Central Coast indicates that the Aboriginal population has distinct health needs.

An adequate survey of Aboriginal health on the Central Coast has not been undertaken. The few surveys which have been done have methodological problems, but indicate that the pattern of illness among Aboriginal people on the Central Coast is different to the general population. For example, in 1990 an Aboriginal researcher, asked 350 people to indicate the illnesses which they had from a list. 51% said they had Hepatitis B (Smith 1990: 30). And last year an analysis of 300 Aboriginal Home Care Service clients showed a different pattern of illness to both Aboriginal and non-Aboriginal people across Australia, especially a higher incidence of respiratory illness (Lincoln-Wright and Hughes 1993)

Health Services

The Central Coast has an extensive range of public and private hospital services, private doctors, government community health services, and a wide range of alternative health practitioners. These are available to all residents, including Aboriginal people, but Kooris are under represented as users of mainstream services.

Broken Bay Aboriginal Corporation, a community controlled Aboriginal corporation, provides a range of Home and Community Care services to local Aboriginal and Torres Strait Islander families, including home delivered meals, respite care, home modification, transport for frail and disabled people.

The Central Coast Aboriginal Branch of the Home Care Service provides domiciliary services including cleaning, shopping, cooking, personal care, home maintenance services, respite for carers for short periods, family support and liaison services.

Some Kooris go to community controlled Aboriginal Medical Services in Redfern or Newcastle, which involves up to two hours of travelling time. At the moment a mobile dental service provided by Biripi Aboriginal Medical Service is visiting the area, and may provide services for about six months.

The Government Area Health Service employs one Aboriginal Health Liaison Worker, and Kooris are under represented in their client statistics.

Aboriginal Health Action Group

A study in 1990 showed that Kooris had special health problems, and often did not use services designed by and for White Australians. (Smith 1990). Kooris saw health needs as the highest priority after land rights, but resources were scarce, and tied to specific projects. In 1992 the Government Area Health Service tried to establish an Aboriginal Health Advisory Committee. This met twice, and was not been reconvened. As they have stated in recent correspondence, communication between Kooris and the Area Health Service has been difficult.

The idea of an Aboriginal Health Action Group emerged about the middle of 1993 in discussion involving local Kooris and a non-Aboriginal academic. Health action groups had been set up recently in Torres Strait, and south of Sydney, and after a couple of months of informal discussion the Action Group held its first meeting in August 1993. From the start the Action Group had a self-conscious Koori identity. As one member put it: 'Well I think if we're a Koori Action Group, ... and we don't hold it here its not going our (Koori) way, is it? It won't look like we're working for Koori'

'Well I think if we're a Koori Action Group, ... and we don't hold it here its not going our (Koori) way, is it? It won't look like we're working for Koori' (940125:1880)

Membership included representatives of Aboriginal organisations, Koori community members and non-Aboriginal people. To remain in the Health Action Group each member must be active, and all agreed that action must be taken to improve local health services for Aboriginal people.

The aims of the Aboriginal Health Action Group are to conduct action research in Aboriginal health and community development, to assist and promote the development of Aboriginal health services, to try out and document ways of doing research suited to the special needs of Koori communities and to undertake other activities as the Action Group determines

Aboriginal Health Action Group - AIMS

- 1. To conduct action research in Aboriginal health and community development [in the study region]**
- 2. To assist and promote the development of Aboriginal health services [in the study region]**
- 3. To try out and document ways of doing research suited to the special needs of Koori communities**
- 4. To undertake other activities as the Action Group determines (Rules)**

Representatives of organisations providing services to sick Kooris had many stories of cultural insensitivity, inadequate services and a general lack of understanding of the needs of Kooris in local health services, particularly those provided by the Government health service. Though some doctors, nurses and other staff in the hospital and community health system were well respected for their awareness of the needs of Kooris, their willingness to help, and their ability to hear what Aboriginal people were saying, there were also complaints of insensitivity, inappropriate behaviour, lack of cultural awareness and sometimes outright racism. Of special concern was the inability of some hospital staff to accept or adjust to the way Koori family and friends relate to an indigenous person who is close to death or who passes away in hospital. In the words of one member:

'You know, it's all the friends. And when somebody is really ill and dying, and everybody wants to be there. And the hospitals they, well, they're not used to that. And they don't cater for that. See that happened when I was losing Mum at the hospital at [town]. The staff said: 'You know you're going to have to tell them to stay away.'" You know my brother-in-law said: 'Look, they're a big family. They're a big mob and they won't stay away.' (940225: 166)

Cultural Sensitivity

***P213: You know, it's all the friends. And when somebody is really ill and dying, and everybody wants to be there. And the hospitals they, well, they're not used to that. And they don't cater for that. See that happened when I was losing Mum at the hospital at [town]. The staff said: 'You know you're going to have to tell them to stay away.' You know my brother-in-law said: 'Look, they're a big family. They're a big mob and they won't stay away.' (940225: 166)**

The treatment available to Koori families is often inadequate and inappropriate. Because of their previous experience, and the experiences of their elders of government oppression many local Kooris are intimidated or afraid to use hospital, health or medical services seen as White services. There is a common belief among local Kooris that people identified as Aboriginal will get a lower standard of care than Whites. This belief is supported by the few health statistics available to them, which show a much worse health status for Aboriginal people, and by many stories of instances of poor care which circulate by word of mouth in the Aboriginal community.

Following informal discussions among people from three Aboriginal organisations and the School of Community Health all Aboriginal organisations were invited to send representatives to an inaugural meeting in August 1993. The Action Group spent the rest of that year planning its direction and composition in broad outline. It was decided that the Group should seek broad support and participation from the local Aboriginal community, should respect indigenous culture and Koori ways, and should work actively for improved Aboriginal health without being committed to one particular way of doing this. During January each Aboriginal organisation was again approached, this time by visiting each one to invite participation. The meeting in February was broadly representative, and the group has continued to widen its membership.

The Action Group is a meeting in which the overworked and stressed staff of Aboriginal organisations can receive support and validation. This helps them to continue in their sometimes very difficult work. It is also the first meeting in the region to achieve general representation from Aboriginal organisations, and is now attracting Aboriginal staff of government agencies to meetings.

As well as the formation of the Health Action Group three other events which are significant for Aboriginal health have happened during 1994. The first was the appointment of the first Aboriginal Health Liaison Worker in the Area Health Service. This person has already played a valuable role in communication between the Aboriginal Health Action Group and Government Health Services, for example, carrying Aboriginal community input to a government strategic plan for Aboriginal health. As well, she provides direct support to Koori users of local public hospitals and community health services. Secondly, the Area Health Service has conducted a series of AIDS and sexual health workshops for Aboriginal young people.

The third event was an extended visit to the region by a mobile dental service operated by an Aboriginal Medical Service. Many Aboriginal people who have bad teeth will not go to a mainstream dentist or a Government dental clinic. This Koori owned and operated service understands the culture of Aboriginal people, and the fear and anxiety some people have about the removal of parts of themselves. Many of the people who make use of the Aboriginal dental service have not been to a dentist for years. Some have put up with pain for a long time rather than go to a dental service which is not culturally OK for them. The mobile dental service was located within the grounds of the largest hospital in the region. Soon after it was installed it became clear that the presence of a team providing a culturally different approach to treatment was difficult for some senior hospital staff to accept. The Health Action Group, together with other Aboriginal organisations, was able to provide support to the mobile dental service, and make representations to the Area Health Service on behalf of the Aboriginal community. The Action

Group is continuing to watch this situation, and is starting to develop skills and potential for local political action.

In May 1994 two doctors, one representing Area Health Services and the other representing private family doctors in General Practice (GPs), attended a meeting of the Health Action Group. This meeting confirmed the Action Group's unease about the Government Area Health Service, but has led to a proposal for a cooperative venture between local GPs and the Aboriginal Health Action Group. Over twenty GPs volunteered for a duty roster, and Kooris have volunteered for receptionist and support roles.

In the meantime, the need for better information about the local Aboriginal community and their health needs was recognised by the Health Action Group. A group of undergraduate students assisted in preparing a community profile, and gained course credit. This is now at the stage of final revision, and will be available for the Health Action Group to use. An invitation has been extended to a student to undertake between three and six months full time fieldwork with the Action Group, and we hope she will help the Health Action Group and Aboriginal Health Liaison Worker produce a statement of Koori needs, goals and objectives in health.

Indigenous Knowledge I

A less obvious problem than racism and disease, but one which may be more important in the long run is the question of Koori knowledge. What Kooris know about themselves and their own health is different to what the Government and health scientists know about them. As one member of the Action Group said:

***P36: You know, different experience. I won't take it out of books. I don't believe in the book.**

***P36: ... The same as all us Kooris here, you know. We all come from different tribes, and some of us. It all amounts up to the same thing. We're black and we've been in the Dreamtime. (940218: 1404, 1440)**

I would like here to point to three different kinds of knowledge, or ways of knowing, In health services indigenous knowledge is overshadowed by two more powerful systems of knowledge: scientific medical knowledge and bureaucratic administrative knowledge. Science is about looking for what causes things. Administrative knowledge is about rational efficiency. According to indigenous knowledge good health is to a large extent a question of relationships and balance.

In a lecture broadcast over national radio last year Mandawuy Yunupingu explained the importance of balance to health and well being, and advised us to 'keep the notion of balance in mind'. (Yunupingu 1994: 2). As an example he used the place near the mouth of a river where salt and fresh water mix. What English speakers call 'brackish water' and Yunupingu calls 'Ganma' is an example of the dynamic balance which is constantly changing with the ebb and flow, with seasonal tides and floods (Yunupingu 1994: 9). Ganma is a metaphor for the relationships between groups and communities, and for the constantly changing state which is good health.

In the scientific view society and culture are opposed to nature. The project of medical science is to overcome the limitations of nature, and overcome disease. But for indigenous Australians, society and nature are not separate. The fundamental task is to restore the natural balance in relationships between human beings and with non-human beings. This will establish a healthy

way of life, corresponding with that which existed before the White invasion. The knowledge needed to do it is often secret knowledge, and is difficult to attain. In urban areas far away from the continuing rituals which maintain the balance of nature in human society it sometimes seems that indigenous knowledge has been lost. But Koori knowledge does operate in the Health Action Group.

In the Health Action Group key decisions are made by consensus. According to the rules:

Decision Making

Decisions of the Action Group will be made at meetings by consensus of the members. If consensus is not achieved the decision will be referred to a later meeting. At the later meeting if consensus is not achieved, the matter may be resolved by the majority of the members present. (Rules)

Consensus decisions are often made on the basis of relationships. At one meeting two different ways of providing health care to local Kooris were proposed. Both were innovative and to our knowledge not tried anywhere else before. One was suggested by a member of the Government Area Health Service and the other by a representative of local private doctors in general practice. Analysis of decision making in the Action Group points to relationships between Kooris and those representing the government health service and private doctors as key element in the decision.

There was no discussion at all about the relative scientific merits of the two proposals, or whether one was likely to be more effective than the other. There was some discussion of the feasibility of each project. which is a question of rational administration. But the factors which dominated the discussion in terms of time and strength of argument related to relationships of respect, trust, and generosity.

The representative of the private doctors came to a number of meetings of the Action Group, listened to the discussion and to what Kooris had to say, demonstrated that he was prepared to give up his time and commented that it cost him potential income to come to meetings and work on the project. Though not previously known, he fairly quickly formed a good relationship with the Kooris in the group, illustrated by their including him in their jokes. On the other hand the representative of the Government health service came to only one meeting. Some Kooris felt they did not trust him, that he did not really care about Kooris, and was doing only what he had to do in his job.

Members of the Health Action Group contrasted western scientific medicine with traditional healing. One member frequently complained of some doctors over reliance on drugs, and several called for traditional healers to be employed. A few short extracts will give the flavour of these calls:

Indigenous Medicine

***P36: ... Now all these doctors, these White doctors, they go through this. There's bush medicine out there that will cure a lot of things. But it's medical they send you to. All these drugs and shit like this. And it does not do it.**

***P53: European drugs are killing us. They're killing us, the European drugs. ... I don't use European drugs. I don't use them.**

***P53: I think we actually need to employ an Aboriginal person that has the qualifications of the bush medicine.**

***P32: I think that needs to be a priority.**

***P53: Oh yes. A top priority. Because the medical centres out there now are still not solving our health problems. (940225: 468, 625)**

Participatory Action Research

Now I would like to discuss the research process itself. Action research helps people to organise the ways they act to change society so that they learn from their experience. It is a way of doing research in which the separation between knowing and doing is broken down. In action research people act for social change and do research to extend knowledge through the same process. Participatory action research involves the people who will be affected by the social change and by the extension of knowledge in all phases of the action research process.

Action research involves repeated cycles through four moments of planning, acting, observing and reflecting.

Plan ⇒ Act ⇒ Observe ⇒ Reflect ⇒ Plan ⇒

In our project, which involved university research into health services, many would expect that scientific knowledge administrative rationalism are all that is needed to understand the situation. As the project has progressed it has become clear that this is not the case. The actions and priorities of Kooris in an urban setting are expressions of a culture grounded in indigenous knowledge. Scientific and rational ways of knowing cannot fully explain indigenous knowledge grounded in a non-Western intellectual tradition of which is tens of thousands of years deep. This knowledge must be approached from within its own terms. We need a way of doing research which can accommodate indigenous ways of knowing. According to Aboriginal researchers including Mandawuy Yunupingu (Yunupingu 1991), and the University of Sydney Koori Centre (Koori Centre 1993) participatory action research can do this. It is a way of doing research which does not demand pure objectivity. Participatory action research can work with subjective view of nature, a view which sees a need for a relationship with a living country, to heal the land and its people through relationship.

The Health Action Group has a self-conscious Koori identity and decision making style and privileges indigenous knowledge over scientific knowledge. For example, in discussion of the size of the Koori population, estimates by knowledgeable Kooris are believed rather than census statistics, as illustrated by the following discussion:

Indigenous knowledge II

***P31: According to the 1986 census ... there's a total of 1,123 (Aboriginal people in the region)**

***P81: How many?**

***P31: Yeah. That's news to me.**

***P81: Be more than that!**

***P31: It says here [local research report] 'leaders of Aboriginal organisations in the area estimate the numbers to be between four thousand and six thousand.' ... And they've got us down as one thousand. (930903: 1231)**

Community members and Aboriginal workers participate in all phases of research. People with respect for Aboriginal culture and knowledge, and who establish truth and knowledge by rules which are different to those of science, place restrictions on the conduct of research and influence the ways in which research is done. The conditions under which research may be conducted are summarised in the box below.

Conditions for research

- 1. All research activity involving the [local] Aboriginal community will be under the control of the Aboriginal Health Action Group.**
- 2. A copy of all research findings and reports completed during or after the period of field work will be given to the Health Action Group.**
- 3. Permission is given for the Health Action Group to use research. Authorship will be acknowledged.**
- 4. Researchers will 'maintain contact with a person nominated by the Health Action Group. (940315)**

Research output on which work has started includes a community profile, a short handbook for Koori action research, and a statement of local Koori health goals and objectives. These will be made available only with the approval of Aboriginal people. Copyright on the community profile, for example, will be vested in the Health Action Group.

Conclusion

This Koori Action Research in Community Health is a project in progress. An Aboriginal Health Action Group supervises and participates in all phases of the action research process, which combines action for change with the extension of knowledge. Participatory action research is a way of doing research which is consistent with indigenous knowledge.

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