# Improving access to primary health care for children and youth: a review of the literature for the Canterbury Clinical network Child and Youth Workstream





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## **Key points**

- Equitable access to primary care has proved difficult to achieve even in well developed countries with advanced health service.
- Minority population groups, and those who are poor, are often disadvantaged
  in access to health services. These groups are likely to have financial,
  geographical, language, and cultural barriers that prevent them from getting
  the health services they need.
- Children are particularly disadvantaged if their parents experience barriers to
  access as they rely totally on their parents to access services on their behalf.
   Māori and Pacific children and those from low-income families, including
  immigrants and refugees are the most disadvantaged in New Zealand.
- There is a range of approaches to improving access to primary care, many of which are described in this report.
- Some initiatives work directly at contacting individuals and families in disadvantaged communities to help them address the barriers to the care they need. These include the health navigator, community health worker, and partnership community worker models.
- Other approaches work to provide services where the barriers are minimised as far as possible. These include nurse-led services, Whānau ora, and youth health services.
- The roles of navigators and community health workers tend to be vaguely defined and have developed to suit particular contexts and populations. They have covered a wide range of tasks, and have used either volunteer or paid, untrained or qualified staff. Many of these roles have made good progress in improving access in specific populations.
- Factors associated with successful interventions include careful planning, good targeting of a particular high needs population, adequate resourcing, and buy-in both by the targeted population and the relevant health services in the area. Having members of the targeted community as the front-line workers, backed by a well-resourced and appropriate range of health services that operate in locations and at hours that suit the community of interest are also of key importance.
- While there are many examples of initiatives in all categories that have reported considerable success, evaluation methods are still underdeveloped.
- Other issues which may be problematic for the front line workers include the
  level and extent of training needed, how they are supervised, hours and
  remuneration, and preventing burnout from community demands. On the
  health sector side, issues include having leadership at a high level, gaining
  commitment and support from the wider health sector, and sustainability over
  the long term.
- It is likely that all the models of improving access have their own merits. It may be that to improve access, a range of different approaches will have the greatest effect.

#### Introduction

This literature review was requested by the Canterbury Clinical Network Child and Youth Workstream in order to develop a fuller understanding of the issues around access as a barrier to child and youth health care and the best way of addressing access for vulnerable populations in the Canterbury area. The following questions were identified as being of interest:

- What are the barriers or other issues for children and youth in accessing health care?
- What is the evidence about effective approaches to improving access for children and youth?
- What is the evidence about the most effective way of improving access for vulnerable populations, including Māori and Pacific children and youth and migrant families, especially those with little English?
- What is the evidence about the effectiveness of the navigator role for improving access to health care for children and youth?

The review is based on material gathered from searching of the Medline and Web of Knowledge databases of international journal literature, New Zealand reports, websites of District Health Boards and primary care organisations, and references cited in retrieved papers. The initial search was conducted in the first week of September 2013 which supplementary smaller searches during September and the first two weeks of October.

# **Defining access**

Access to health care has been defined as the degree to which people are inhibited or facilitated in their ability to gain entry to and to receive care and services from the health care system (Medline database definition). Andersen (1995) notes that access is a relatively complex health policy measure in which potential access (the presence of health care resources) must be distinguished from the availability of enabling resources that provide the means for their use and increase the likelihood that realised access – the actual use of services - can take place. Both health system and personal enabling resources are needed for realised use of health care services. In other words, health providers and facilities must be available where people live and work, and people must know of their existence and have the means to get to them.

#### Barriers to access of health care services

Access to primary health care is central to the World Health Organisation's strategy and vision of strengthening health systems to provide "Health for All" (Mahler 1981) but equitable access has proved difficult to achieve (Jatrana & Crampton 2009). It is well documented in both New Zealand and internationally that not all groups in society experience equal access to health care services. Even in the richest countries, the better-off live several years longer and have fewer illnesses and disabilities than the poor. Poverty is the biggest risk factor for poor health, and income-related differences in health are a serious injustice and reflect some of the most powerful influences on health (WHO 1998).

Goddard and Smith (2001), in their theoretical work on access, provide a useful list of supply-side variations in access that may affect equity of access to health care services:

- Availability: health care services may not be available to some groups, or clinicians may vary in offering treatment options to people with identical needs but from different population groups
- Quality: the quality of certain services offered to identical patients may differ between population groups
- Cost: the health care services may impose costs both financial and otherwise – that vary between population groups
- Information: health care services may fail to ensure that the availability of certain services is known with equal clarity by all population groups.

New Zealand has a largely tax funded health system. General practice based primary healthcare is 60% Government funded and 40% funded by patient co-payments. Patient co-payments, however, coupled with a paucity of Māori and Pacific staff and the uneven distribution of general practitioners (GPs), have resulted in significant financial, cultural and geographical barriers to access in some regions (New Zealand Child and Youth Epidemiology Service 2011). Using data from the Survey of Family Income and Employment (SoFIE) Jatrana and Crampton (2009) found that financial barriers to primary health care existed for "a substantial subgroup of people" surveyed (p. 8) who reported that they put off going to the doctor or collecting prescription medicines because they could not afford the co-payment.

Structural barriers to accessing health care include geographical barriers when services are located far away and the patient needs to have the time and a means of transport to get to them. This a particularly important barrier to those who live in rural areas, and is exacerbated still further in relation to after-hours and specialist services. For example, living far away from health services has been found to result in patients with various types of cancer being more likely to delay seeking care and therefore having a late diagnosis, and being more likely to forego follow-up care because of the time and costs of travel (Haynes et al 2008; Baird et al 2008; Mathews et al 2009). Long transport times also have financial implications in terms of transport, accommodation, and other costs such as childcare.

There may be barriers in being unable to get an appointment in a timely manner to the services that exist if they are insufficient to meet the need of the local population. Poor coordination of health services also creates a barrier to access. Health services spread over different locations, failure to locate records when the patient attends, long waiting times, and the ordering of x-rays and other tests that require multiple trips on separate days compound the difficulty for those who already experience barriers to accessing health services (Veitch et al 1996; Toomey et al 2013).

Language and communication may create important barriers, as they affect all stages of health care access, from making an appointment to filling a prescription (Morris et al 2009). Understanding what is being said, reading instructions about medicines, and the ability to understand and complete documentation affect those with low literacy skills as well as people from other language groups. Cultural beliefs about health care

that differ from the predominant culture of the health system can also be a barrier to accessing health care for minority groups and new immigrants or refugees. Previous negative experiences with health care providers are likely to compound these barriers (Spenceley 2005).

## Barriers for child access to health care services

Children depend entirely on their parents in infancy and childhood to ensure they receive health care. Good child health is vital for health in adult life and childhood is the opportunity for preventing many of the risk factors that result in adult diseases. Poor child health and development also has an influence on broader social outcomes, such as educational achievement, mental health, and employment opportunities, but if neglected contributes not only to physical and mental illness, but also unemployment, violence and crime (New Zealand Child Health Strategy 1998). Children in population groups that are already disadvantaged therefore are particularly vulnerable. In New Zealand the most disadvantaged populations of children are those from Māori, Pacific and low income families including those from migrant and refugee families.

The Child Poverty Action Group (2008) has noted the widening income gap between the well off and the poor in New Zealand, and the particularly detrimental effect it has had on children. The Child and Youth Epidemiology Service has also highlighted that New Zealand children and young people experience large socioeconomic and ethnic disparities across a range of conditions including hospital admissions for infectious and respiratory diseases, dental caries, sudden unexpected death in infancy (SUDI), hospital admissions for assault, and injury mortality (Craig et al 2013). Moreover, the indicators used to measure disparities do not fully capture the extent of unmet need among children, particularly those with disabilities or mental health issues (Craig et al 2013, p. 25). Improvements in child health are therefore critical in reducing health inequalities and initiatives need in particular to target populations of low income Māori, Pacific and other low income children and their families (Pocknall 2009).

## Current models of care for children and young people

There are two points of contact with primary health care that are available for children. WellChild/Tamariki Ora contracts funded by the Ministry of Health and the additional primary health care services are accessed as children get older through health nurses in schools or in the community. They can also be enrolled with a Primary Healthcare Organisation (PHO). PHOs receive a subsidy for free care to under 6 year olds which is available to all participating PHOs as an incentive to ensure young children can access timely and adequate primary health care. Access for children to a PHO is, however, dependent on their carer initiating contact with the service and so barriers to adult access are also highly relevant for children (Craig et al 2013).

Craig et al (2013) in their study of the health status of children and young people in New Zealand identified a range of barriers to health care access related to convenience, timeliness, cost, after-hours access and cultural needs. They found that children under the age of 15 years were over-represented in hospitalisations that could have been avoided (ambulatory sensitive hospitalisations or ASH). The study noted

that ASH rates are considered to be one measure of the effectiveness of primary care, but they are a measure of failure (Craig et al p. 94). Inability to pay was likely to contribute to a delay in seeking medical care and therefore to more serious outcomes for the child, or to inappropriate attendance at a hospital emergency department where care is free.

## Approaches to improving access to care for underserved populations

The following sections examine a number of approaches to improving access to health care for disadvantaged populations. Literature on health navigators, community health workers, partnership health workers, nurse-led initiatives, whānau ora, and youth specific health services is reviewed. New Zealand research is highlighted where possible and representative examples provided from the international literature. These focus on child and youth health where possible, but it would have been unnecessarily limiting if examples were limited to these alone. Other interventions have been chosen because they show a way of applying a particular model to a disadvantaged population that may be useful. It should be emphasised that it has not been possible to provide comprehensive coverage of all these areas within the scope of this report. A final section offers a summary and some conclusions derived from the literature.

#### Patient navigator programmes

Navigator roles originated in secondary care as a way of assisting minority or underserved patients with cancer. These groups were known to be financially, culturally, linguistically and educationally disadvantaged in interacting with the complex sectors of the health care system that detect, diagnose, and treat cancer. The cancer navigator role is described in some detail in this section as it is relatively well established and more general interventions have been developed from applying the same model in other circumstances. According to Natale-Pereira et al (2011) there are four broad areas where navigators can contribute most to eliminating disparities in cancer outcomes: prevention and early detection; health care access and coordination; insurance coverage; and diversity and cultural competency. Navigator roles in cancer aim to increase screening uptake, speed up diagnosis after initial test results and facilitate the patient journey through the health system throughout treatment and follow up. If the time to diagnosis can be shortened, for example, disparities at the stage of diagnosis can potentially be reduced and cancer outcomes improved. The navigators described in the cancer literature may be trained lay people from the target community (Bone et al 2013; Fiscella et al 2012) or nurses working from inside the health system (Thygesen et al 2012a; Hook et al 2012). .

According to Dohan and Schrag (2005) patient navigators differ from other social support workers and care coordinators in that they take a flexible approach to solving whatever problems arise rather than delivering a pre-defined set of services. The patient navigator literature in the area of cancer is primarily from the United

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<sup>&</sup>lt;sup>1</sup> Interpersonal navigation needs to be distinguished from virtual navigation (Loiselle et al 2013) tools for patients to provide online information and support. These are not aimed at disadvantaged populations and are likely to be inaccessible for those with low levels of literacy in English.

States and focuses on underserved minority populations who have inadequate or no health insurance. Navigators have worked at addressing cultural, educational and language barriers to screening and reaching people who are disconnected from the health system. Many navigator programmes match patients with navigators of similar ethnic and racial background, for example, the Native Sisters (Native Women's Wellness through Awareness Project) Burhansstipanov et al 1998; Burhansstipanov et al 2000; and Dignan et al 2005). This programme works with Native American women to increase their rate of cancer screening using both face-to-face and telephone contact.

A number of randomised trials and other controlled studies have shown that the intervention groups who were assigned to navigators had reduced time in resolving abnormal screening results, reduced time from abnormal results to definitive diagnosis, and fewer delays in treatment (Raich et al 2012; Ramirez et al 2013; Dudley et al 2012; Whop et al 2012; Warren-Mears et al 2013). All patients in these studies were low income minority and/or indigenous populations in the United States who were uninsured or under-insured and received help from a lay navigator. Patient satisfaction was high, particularly in those people with low English proficiency (Hook et al 2012; Thygesen et al 2012a; 2012b; Fiscella et al 2012). However, there was a tendency for patients to feel let down and disappointed when their treatment finished and they lost the connection with their navigator (Thygesen et al 2012a; 2012b).

Dohan and Schrag (2005) list eleven navigator programmes in eight different states of the US. Seven programmes used lay or peer navigators, and three used bilingual and bicultural navigators in Spanish or Cantonese speaking communities. Five programmes had been evaluated at the time of publication, and these suggested favourable outcomes in improved rates of screening and follow-up for patients as well as the relevant health service's ability to engage, track and support patients, and to communicate with and build trust with disadvantaged populations. Difficulties with evaluation were noted, including the need for a fuller definition of the navigator role, and the development of appropriate measures of service effectiveness and cost effectiveness in particular population groups.

#### Navigators in primary care

A number of New Zealand District Health Boards have implemented navigators in primary health care. While only some of these navigators are specifically aimed at children and young people, all are directed at high needs populations. One example is that implemented by the West Coast District Health Board. The service employs four lay navigators, who are well known locally and familiar with available services. They support patients with complex clinical and social issues affecting their ability to access healthcare and social support in the sparsely populated region. Originally targeted at patients with cancer, this has now been extended to take in other patients with long term care needs. Most patients (around 59%) are referred through GPs, and guidance ranges from form filling to helping resolve a dispute between a patient and their Work and Income Manager. Patient satisfaction appears to have been high and patients are reported to have been less stressed once barriers to care were sorted out and they could concentrate on getting well. A forthcoming publication (Doolan-

Noble et al 2013) <sup>2</sup> reports on this service, describing its evolution, purpose and effects based on utilisation data, survey results, and interviews with the navigators. The author has noted that after seeing this model in action, she concluded that the service may add value to the currently stretched workforce in primary care, particularly in a sparsely populated rural region such as the West Coast.

There are other examples of health navigators in New Zealand DHBs. East Tamaki Healthcare <sup>3</sup> in Auckland, for example, is highlighted in the Ministry of Health (2011) publication *Better Sooner More Convenient Health Care in the Community*. The service aims to provide their high needs population with acceptable, affordable, and accessible primary health care. Their strategies to improve access include clinics located in shopping centres with adjacent public transport, a walk-in service with no appointments required, a low fee structure, linked information between clinics so that patients can attend any clinic, extended hours, and cultural support provided by clinical family navigators. According to their website the navigators are mostly overseas trained GPs and nurses who are not yet registered in New Zealand.

Navigators are also used in the Whānau ora services delivered by Whakapai Hauora Charitable Trust in Palmerston North. <sup>4</sup> This service has a particular focus on working with Māori who are not accessing primary care services and linking them either with general practice services or alternative health care teams, The service aims to:

- Improve access to primary health care services for unenrolled Māori and their whānau
- Improve the health status of un-enrolled Māori and their whānau, particularly the under 30 year old age group
- Facilitate entry to effective primary health services for high needs whānau and to other professionals as appropriate
- Identify barriers to accessing primary health services, and champion the need for other services such as housing
- Draw on existing networks and connections to encourage collaborative efforts for high needs whānau (Adapted from website).

Navigator services in primary health care described in the international literature follow much the same model as those in cancer screening and diagnosis but the literature is relatively sparse (Manderson et al 2012). One of the best developed examples is the 2-1-1 service telephone service in San Diego (California) that assists callers to access health-related services and public assistance benefits (Rodgers and Purnell 2012). The service serves a low-income population where disparities such as poverty and chronic stress are exacerbated by the number of people who do not have citizenship. Not only is awareness of services low, but services are fragmented and residents often face lengthy eligibility and enrolment procedures. Additionally, most who use the service have linguistic and literacy difficulties. The service is telephone only and does not recruit clients but deals only with those who call them.

<sup>&</sup>lt;sup>2</sup> This study was not yet accessible in full text using local resources and the abstract from the journal website provided only minimal information. There has also been a report in New Zealand Doctor.

<sup>&</sup>lt;sup>3</sup> See <a href="http://www.ethc.co.nz/27/Pathway-of-care">http://www.ethc.co.nz/27/Pathway-of-care</a>

<sup>&</sup>lt;sup>4</sup> See http://www.whakapaihauora.maori.nz/information/whanau-navigator-service-i-27.html

There are two arms to the service. A Benefits and Enrolment Department helps eligible clients get access to public assistance programmes. An innovative partnership with the San Diego County has enabled clients to provide information by phone so that a staff member can complete applications online and submit them with a recorded telephonic signature. The other arm of the service works with community partners to provide a single access point for health-related information and referral to services. Information and assistance is provided with obtaining insurance, prescription medicines, food and transport needs, child or elder care, appointment scheduling and personal finance. Clients with complex needs are provided with a "concierge" service, which gives assistance in multiple areas for a greater length of time and on a more personal level than with other calls. In the first two years of operation, the service recorded over 13,000 calls. During the months November 2010 to December 2011, 462 follow-up calls were made to assess client satisfaction. Eighty-four percent of those had followed through on at least one of the referrals provided and of these, 39% received the assistance they needed, with 45% still awaiting an outcome. Nearly all (92%) said that they were better able to manage their needs for health services as a result of contacting the 2-1-1 programme. There was no information reported in this paper on how the service is publicised or funded.

In another intervention (Dembe et al 2012), a coalition of employers in the hotel and restaurant industries collaborated with community organisations to improve access to basic healthcare services for low-wage Latino workers in Ohio. Using grant money from the Robert Wood Johnson Foundation, the project linked workers in participating companies with a qualified Hispanic health navigator. The navigator facilitated health care screening, health education, provided information about available assistance, and referred participants to medical providers including making appointments for them. The pilot programme was successful in increasing the workers' knowledge of eligibility for assistance programmes, appropriate use of primary care and emergency department services, arranging appointments for participants and following these through to ensure that the participants attended. Limitations were the long wait time from referral to being seen by a community health service, especially mental health services, and the withdrawal of several of the participating employers because of the economic downturn in 2008-2009. Transport to appointments at a clinic proved to be a particular barrier even with the involvement of the navigator. After the project finished, only a limited version proved to be sustainable with a combination of public and private donations, a small amount of employer subsidy and modest user fees.

A study by Henderson and Kendall (2011) in Queensland examined the role and lived experience of nine community navigators who were trained by and worked with NGOs in four culturally and linguistically diverse communities in Logan, Queensland. The communities included Sudanese, Burmese, Pacific Island, and Afghan people. The navigators' role included assessing client needs, facilitating health promotion, supporting community members to access health services, supporting GPs with the use of interpreters, and making referrals to health services. The service was very successful with the relevant communities; the navigators became knowledge brokers not only in health but on many other social issues such as accommodation, employment, and financial problems, as well as generating activities to build capacity and empowerment for the future. Community members looked to them to sort out any

problems with health and social services, such as accompanying them to hospital or to social or welfare services to interpret and advocate for them. However, the commitment and altruism of the navigators led to them spending far more time than they were employed for helping community members, often to the detriment of their own families. Many of them became stressed and overloaded by their success and did not believe they could sustain the role long term. They were paid for only 11 hours per week but most worked up to 50 or 60 hours and were unable to hold other employment because of the demands of the community. Educating the navigators about how to place boundaries around their work placed them under even more stress because they then could not meet the expectations that the community had learnt to place on them. The study found that:

"if we wish to draw on lay helpers to address inequity and access barriers for CALD communities, we need to understand that the success of the role comes with serious personal implications for which they must be adequately compensated. It is important to address this dilemma, because the role offers such significant potential for addressing access barriers and bringing about health reform for CALD communities." (Henderson and Kendall 2011, p. 54)

In a very different approach, a systematic review of randomised trials of nine navigator programmes for adults with chronic disease was conducted by Manderson et al (2012). These programmes aimed to identify, anticipate, and address barriers that were likely to occur in the transition between hospital and home services and afterwards, not only for patients, but also for caregivers. The programmes were different from those described above in that the navigators were not community members but qualified nurses or social workers. Although described as "navigation roles" in the article, the job titles carried names such as "transition coach" or "guided care nurse". The shortest programme lasted 28 days post-discharge and the longest 18 months. The programmes were assessed for economic effectiveness (eg. time to readmission, number of hospital days per patient), psychosocial improvements (quality of life, adherence to self-care, reduction in depressive symptoms), and functional improvements (IADL and physical functioning). The outcomes were mixed, with the best outcomes resulting from longer lasting studies that began prerather than post-discharge. This study is another example of the applicability of the navigator model across a range of populations with high health needs. However, it did not specifically address minority or low income groups.

Another example described as a navigator intervention provided bilingual navigators to low income, Spanish speaking patients who attended community health centres in Denver, Colorado (Shlay et al 2011). Three hundred and forty intervention patients identified as having cardiovascular health risk behaviours were each matched with a trained navigator who provided individualised counselling, assistance in goal setting, and referral to community resources. Physical activity, nutrition and smoking cessation counselling were given, free gym memberships were provided and participants were encouraged to attend primary care when appropriate. At baseline and 12 month follow up participants were compared with 340 similar patients with usual care only. At follow up the intervention group was reported to have better nutrition habits and more readiness to exercise than the comparison group, though tobacco use and smoking cessation attempts did not improve. The outcome measures and the results of this study were poorly reported, with the "significant improvements

in nutrition measures" (p.5) in the intervention group not being supported by any published data.

### Community health workers

The navigator role has considerable overlap with the community health worker (CHW) role, the primary difference appearing to be the more general health promotion that CHWs frequently take on in communities such as screening for diabetes, and delivering classes in nutrition, first aid and accident prevention. Zuvekas et al (1999) define a CHW as "a trusted and respected community member who provides informal community based health related services and who establishes vital links between community-based health providers and persons in the community"(p.33). CHWs have been known by a wide variety of titles, including community health advisors, community outreach workers, lay health workers, village health workers, promotoras (in Hispanic communities in the United States), and others. Roles of CHWs described in the literature cover a wide spectrum: outreach and case finding, community health education, translation, arranging transport, connecting people to social services, and sometimes case management under the supervision of a nurse or social worker. They may be fully paid, partly paid, or volunteer, formal or informal, lay or professional. There is a focus on contacting populations that have little or no contact with primary health care services. CHWs usually spend most of their time out in the community but may be linked with a medical service where they book appointments for patients, send reminders, and liaise between different parts of the health sector on behalf of patients.

A major review by the WHO (Lehmann and Sanders 2007) drew together the main evidence from the extensive and diverse literature on the effectiveness of the CHW role.<sup>5</sup>

- The CHW role may be as a generalist, delivering a range of services that can be preventive, curative or developmental, or specialists, focusing on a single or small number of interventions such as promoting vaccination, prevention of diabetes, or promoting cancer screening.
- There is robust evidence that CHWs can improve access to basic health services and can undertake actions that lead to improved health outcomes, especially, but not exclusively in child health.
- To be effective, CHWs must be carefully selected, appropriately trained and adequately and continuously supported. Large programmes require substantial support for training, management, supervision and logistics.
- CHWs are not a panacea for weak health systems nor an inexpensive option to
  provide access to healthcare for underserved populations. Programmes have
  failed through unrealistic expectations, poor planning, and underestimation of
  the effort and input required. This has sometimes undermined the credibility
  of the CHW concept.

<sup>5</sup> The WHO report related particularly to low and middle income countries, with case studies drawn from Brazil and China, but also included some disadvantaged and underserved populations in high income countries.

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- CHW programmes must be driven by and embedded in the communities they serve, but struggle where the community is given the sole responsibility for mobilising and motivating their members
- The question of whether CHWs should be volunteers or paid is controversial. CHWs are generally poor and trying to support their own families. There is no evidence that volunteer programmes can be sustained over the long term. Although CHWs may be expected to spend only a small amount of time on health-related duties, community demand often becomes all-consuming leading to burn out. Community financing programmes have been tried, but have rarely been successful
- Existing evidence suggests that CHW programmes are not cheap or easy, but remain a good investment, particularly as the alternative is often no care at all for the poor. Political leadership and substantial and constant provision of resources are needed, as well as longitudinal evidence as at present there is a knowledge gap in relation to what works and what does not (adapted from Lehmann and Saunders 2007, p. v-vi).

A Cochrane systematic review (Lewin et al 2010) examined 82 studies on the effect of lay health workers on maternal and child health and infectious disease. The studies examined were of interventions in low income or disadvantaged populations in high income countries but also included some from low and middle income countries. Included studies were limited to randomised trials and lay health workers were defined as those who were trained in some way in the context of the intervention but had no formal professional or paraprofessional qualification.

The review found that compared to usual care, lay health workers would:

- Probably lead to an increase in the number of women who breastfeed their children
- Probably lead to an increase in the number of children who have their immunisations up to date
- May lead to slightly fewer deaths among children from fever, diarrhoea and pneumonia
- May lead to fewer deaths of children under five years (from all causes)
- May increase the number of parents who seek help for their sick child
- Probably lead to the number of people with tuberculosis who are cured.

A follow up Cochrane synthesis of qualitative studies is in preparation by a Cochrane group aims to identify, appraise and synthesise qualitative research evidence on the barriers and facilitators to the implementation of lay health work programmes for maternal and child health.

Aside from these major pieces of synthesis, four representative studies from the substantial international literature are outlined below. Two demonstrate the generalist, and two the more specialist role of the CHW.

Hesselink et al (2009) examined the effect of community health workers (termed ethnic health advisors in this study) in four districts of Amsterdam with hard-to-reach ethnic minority populations. Using a participatory action approach, each district developed its own version of the health worker position based on their own community context. Eleven advisors were appointed to work 16-24 hours per week

each. Their ethnicity corresponded to the main migrant groups in each of the four districts: Moroccan and Turkish in three districts, and Ghanaian and Surinamese in the fourth. Over the two years of the study, the advisors made personal contact with 2,224 inhabitants, of whom half were referred to health and welfare services. Over 500 group classes were also run, mostly attended by Moroccan and Turkish women. Outreach activities and office hours at popular locations were the most successful strategies for reaching the target population. It proved important also to have a well organised service to refer clients to, as well as commitment and support from local health and welfare services.

Another recent report found that improved asthma management had resulted because of a CHW intervention among disadvantaged inner city children in Chicago (Margellos-Anast et al 2012). Seventy African-American children with an average age of 7.3 years were enrolled in the study. The children had an average of four emergency department attendances, hospitalisations, or visits to a physician for acute exacerbations during the previous year, and over half of them lived with a smoker. Two CHWs were recruited with cultural connections to the target communities. They received 5-days intensive training in aspects of asthma management and continued to meet with educators throughout the project to reinforce their understanding and skills. The CHWs visited each family at home three to four times over six months to teach children and their families about managing asthma in an understandable and culturally appropriate way. They talked about how asthma developed, how to recognise symptoms and early warning signs of exacerbations, asthma triggers and how to avoid them, the concepts of quick relief and long term controller medication and correct inhaler use. They also worked with the family to link them to a primary care physician and establish an asthma management plan. The intervention resulted in improved asthma control, with reductions in symptom frequency and the use of emergency health care. Median urgent health care utilisation fell by 75% compared to the year prior to the intervention. There were also improvements in the children's quality of life, exposure to triggers, self-efficacy of the family in managing asthma, and in asthma medication technique. Moreover, the intervention proved to be cost effective, with \$5.58 saved per dollar spent. Although the absence of a control group was identified by the investigators as a limitation, they were able to conclude that:

... the implicit benefit to the community resulting when community residents are hired and trained to perform a duty cannot be undervalued. Such benefits include improved economic stability as jobs are created, increased power and control over health and an increased knowledge base in the community. (p. 388)

A year-long culturally tailored CHW-conducted intervention was run by the Wai'anae Coast Comprehensive Health Centre to improve diabetes management in Native Hawaiians and Samoans (Beckham et al 2008). The intervention was designed to address not only the disproportionately high rate among these population groups but also their low rate of participation in diabetes education and management programmes compared to the European and Japanese populations of Hawaii. The centre is located in a designated underserved area and has the highest proportion of households in Hawaii that received financial aid and food stamps. It also has an average annual per capita income well below that of the state and a large proportion of the adult population with obesity and/or diabetes. Eligible participants (n=116) were contacted

by the health centre, of whom 80 agreed to participate. Those that declined served as a usual-care control group. Three CHWs, all of Hawaiian or Samoan ethnicity and long-time residents in the community, were chosen to work on the intervention. The CHWs received a 6-month training programme including a component of diabetes specific material. Throughout the project they met once every two weeks for inservice training and case conferences with a multidisciplinary team at the health centre.

Participants were visited at home by the CHW. It was important that the process was unhurried and that the Hawaiian custom of "talk story" was observed to establish rapport, assess barriers to care and the amount of social support available. The CHW and the participant and their family would then jointly identify achieveable goals and develop a plan of action that took into account the patient's knowledge, desire to change, and living circumstances. Typically, plans included blood glucose monitoring and targets, diet, exercise, information about medications and preventive health measures. Cultural customs and dietary preferences were taken into account and the wider family involved whenever possible, for example, by providing and discussing recipes. Participants were offered access to services provided by a traditional Hawaiian healing centre, which included traditional remedies for diabetes as well as spiritual and conflict resolution aspects. They were also connected with the primary care service, and had transport provided if necessary. Over the course of the project the CHWs made an average of 4.24 visits per patient with each visit lasting 1-1.5 hours. The supportive services were well used, with many visiting a dietician, over half making use of free transport to visit primary care, and almost half using the traditional healing centre. The 72 participants who completed the intervention had a significant reduction in HbA1c compared with baseline  $11.06 \pm 0.8\%$  at baseline to  $8.86 \pm 1.7\%$  (p<0.01). In the comparison group (those that declined the intervention) HbA1c showed a non-significant decrease from  $10.86 \pm 0.7\%$  to  $10.46 \pm 1.3\%$ . The CHWs appeared to be a key factor in the improvement because they were able to spend the length of time needed to provide culturally appropriate patient education, which resulted in positive outcomes for the participants. The authors noted that this was not generally possible in a modern health service and concluded that CHWs are a "vastly under-utilised resource" (p. 425) in providing culturally appropriate care for underserved, ethnic and racial minority populations. There was no information in this paper about the reimbursement of the CHWs or the hours worked, but the Bureau of Primary Health Care<sup>7</sup> was acknowledged for their support which suggests that the service was supported with government funding.

In the final example of CHW interventions, Zuvekas et al (1999) examined a purposive sample of seven organisations across the US that worked with CHWs. They looked at the approach each one took to increasing access, use of services, and patient knowledge and behaviour for disadvantaged populations. Six of the organisatons took a generalist approach to providing a wide range of services, and one

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<sup>&</sup>lt;sup>6</sup> An informal unhurried conversations as a prelude to discussing business; in *talking story*, ideas, stories, and opinions are shared in the search for common ground (see Beckham et al, p.420)

<sup>&</sup>lt;sup>7</sup> The Bureau of Primary Care is part of the US Department of Health and Human Services which funds health centres in underserved communities for low income or uninsured or have other obstacles to accessing health care. See <a href="http://www.hrsa.gov/about/organization/bureaus/bphc/">http://www.hrsa.gov/about/organization/bureaus/bphc/</a>

focused on aspects of sexual health among young people. In some programmes the CHWs were full time paid employees, but in most they were volunteers paid only a small stipend to cover expenses. Most of these programmes covered assistance to individuals to gain access to health and social services or public assistance programmes as well as conducting general health promotion and education. Populations targeted were mainly pregnant women and children, homeless people, and migrant farm workers. This article is not a formal evaluation of the various programmes but indicates some lessons that were learned from them:

- Community participation in needs assessment and planning of a CHW intervention improves acceptance of and cooperation.
- When CHW's activities are integrated with a primary health centre, patients are less likely to miss the appropriate health and social services and more likely to receive follow up of their needs.
- The time that CHWs spend out in the community must not be compromised by time spent in the health centre. The two must be balanced.
- It is vital that administrators are realistic about what CHWs can achieve so that they do not suffer burn out.
- CHWs need to be recruited from the target community and have shared life experiences with them. Personal qualities such as communication skills, determination, pragmatism, logic and being compassionate and respectful are essential attributes; other administrative skills can be easily taught.
- Training is most successful when it blends general skills with training relevant to the particular task. After initial training, new CHWs should shadow a more experienced CHW for a period.
- Supervisors of CHWs need to have been involved in programme planning and have a full understanding of what the role requires. Senior management needs to recognise that some CHWs may never have worked in a professional role previously and supervisors will initially need to spend considerable time guiding them.

#### The Partnership Community Worker (PCW) programme in Christchurch

The Partnership Community Worker model in Christchurch was implemented by Partnership Health PHO as part of their Services to Increase Access (SIA) initiative. The service is ongoing, now run through Pegasus Health since the merger with Partnership Health. The initiative is targeted at people who are not enrolled in a general practice, or those who are enrolled but not visiting general practice as often as needed. An evaluation of the PCW initiative was carried out at the end of 2009 and examined the years 2007/8 and 2008/9. The evaluation drew from a review of key documents, surveys of practice nurses, GPs, and social service organisations, a focus group discussion with practice nurses, interviews with the PCWs host organisations and with a number of key members of Partnership Health and Pegasus staff. During the two time periods covered by the evaluation 2,470 and 2,290 people respectively were registered with the SIA initiative. However, these included not only those reached by the PCWs but also that were reached through additional practice nurse funding that formed a separate part of the SIA initiative. The following section summarises the findings of the evaluation in relation to the Partnership Community Workers only.

At the time of the evaluation there were 16 PCWs based in 14 community agencies. Combined hours worked amounted to 8.15 FTE. Their role had many similarities with both the navigator role and the CHW examples described in the sections above. However, unlike like most of those examples, all the PCWs had some type of formal qualification. As well as linking people with primary care, they assisted with wider social needs including housing, transport to hospital and medical appointments, food, clothing, facilitating the obtaining of benefits from Work and Income, filling out forms and providing budgeting advice. The evaluation found that PCWs were respected by all the services they worked with and their effectiveness was highly rated in social service organisations. PCWs had access to and were able to connect clients to a wide variety of services and this direct support was felt to have been a valuable contribution in achieving good social and health outcomes. GPs and practice nurses reported that they generally had positive relationships with the PCWs and appreciated having access to their knowledge and connections to social services. They believed that the PCWs had improved access for their enrolled patients who had not been accessing the care they needed. The people skills of individual PCWs had a significant impact on how the service was perceived. However, the evaluation also found that the PCWs had experienced difficulties in building relationships with some general practices, and not all GPs were aware of the initiative. Additionally, some practice nurses and GPs did not appreciate that the PCWs had formal qualifications<sup>8</sup> and had assumed that they did not.

The evaluation made the following recommendations:

- That the PCW initiative should be continued and expanded
- That the option of placing a PCW in a general practice should be trialled
- That there should be work to increase general practice awareness of the PCW initiative
- That practices who currently work with PCWs should help promote the initiative to their peers
- That mechanisms should be developed to ensure Pegasus staff receive and circulate appropriate information about PCWs
- That PCWs who do case work should have professional training and experience in case management and belong to a professional organisation.

## Nurse-led models of care

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Nurse-led models of care is an area to which the New Zealand health sector has assigned resources in recent years and there is now a number of examples of expanded roles for nurses in improving access to primary health care. In 2003, the Ministry of Health made contestable funding available for the development of primary health care nursing innovation projects that would allow new models of nursing practice to develop, reduce fragmentation and duplication of services, and "assist in the transition of primary health care delivery to PHOs" (Primary Health Care Nurse Innovation Team 2007, p.v). Eleven innovative projects were funded,

<sup>&</sup>lt;sup>8</sup> The type of qualification was not detailed in the evaluation.

<sup>&</sup>lt;sup>9</sup> Note that increasing access and/or reducing disparities in health was not in fact overtly mentioned in the goals set by the Ministry of Health, but seemed to have been understood that this was the general direction of the expansion of models of primary care nursing.

seven of which provided nursing services to high needs populations that were known to experience barriers in accessing existing primary care services. The various projects were located in Turangi, Reporoa, Taranaki, Tairawhiti, Wairarapa, Hutt Valley, and Reefton. They each ran for three years and an evaluation of them was published in 2007. The projects, are escribed in more detail in the evaluation report.. Criteria for success were how well each one met the Ministry's goals, the extent to which it met the objectives of the Primary Care Health Strategy and the objectives set by the individual DHB, and whether the project was sustainable. All projects achieved some success, and most were well attended and valued by the communities served. All also met the DHB objectives set though some needed to be refocused midterm and some also made good progress against the Ministry's goals.

The evaluation concluded that the key factors for success were:

- Nursing leadership at either a clinical or organisational level
- The support for the innovations within the DHB and PHO
- The establishment of clinically sound systems which connected services
- Consultation and collaboration with local communities of interest.

The main barriers to the development of the initiatives were the early stage of development of the PHOs (at the time), the diversion of nurses into the Meningococcal B vaccination programme, the shortage of nurses with the right skills, particularly the shortage of Māori and Pacific nurses, and, in some projects, lack of buy-in from nurses and other health providers.

Since these initiatives, there has continued to be an emphasis of developing nurse-led services in primary care. The document *Better, Sooner, More Convenient Care in the Community* (Ministry of Health 2011) features several case studies of programmes where nurses assess patients independently and manage long term conditions in partnership with GPs. Craig et al (2013) in their review of models of primary health for children in New Zealand also draw attention to nurse-led programmes targeting disadvantaged children. They highlight several highly successful examples of nurse-led initiatives: integrating lead maternity carers and well child immunisation at the practice level in South Auckland; a nurse-led secondary prophylaxis programme for rheumatic fever in Counties Manukau; and a nurse-led service across four clinics which provides first contact services for the rural community around Reporoa. <sup>10</sup>

Another example of a nurse-led initiative to address disparities for high needs Māori, Pacific and NZDep quintile groups 4 and 5 children and their families in Hawkes Bay was been reported by Riley and Crawford (2010). The medical centre that implemented the nurse-led, child specific clinic focused on their high number of enrolled children with chronic and recurrent morbidities. Children frequently did not attend medical appointments and there was high use of after-hours services. All children under 18 years who were identified as having chronic conditions were offered an extended appointment of 45 minutes with the new clinic. The consultation gave time for discussion, education, and to offer preventive strategies. Wider social concerns such as housing, transport, smoking cessation, the need for financial assistance and family violence screening were also addressed where possible. Extended hours were offered and opportunistic assessments outside the normal child

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<sup>&</sup>lt;sup>10</sup> This Reporoa service is one of the seven described in the previous paragraph.

health clinic hours were also conducted. International indicators and scoring systems were adopted to measure baseline and follow up morbidity. An audit after the clinic had been running for 18 months demonstrated a significant (>30%) reduction in eczema severity, daily irritability and daily occurrence of pain. Post-intervention, fewer children were hospitalised and there was a 50% reduction in antibiotic use. The GPs who worked within the practice agreed the nurse-led clinic had positively assisted them, including with their workload. The study concluded that the key factors that had effected positive change in the children most in need had been the extra time the nurses had been able to spend with children and their families, and the provision of opportunistic assessments whenever possible.

As a comparison with the New Zealand studies, a few representative examples of similar interventions from the international literature are described briefly. A review of evaluations of nurse-led walk-in centres in the UK was reported by Desborough et al (2011). At the time of writing, there were 43 of these centres in the UK, the majority of which were nurse-led though a few also employed a GP. The review of thirteen publications on their effectiveness concluded that the results had been disappointing. The clinics appeared to have been poorly targeted - they were not in underserved areas, were not attended by the most disadvantaged groups in the population and did not appear to have reduced demand at emergency departments or the workload or waiting times at nearby medical centres. The reviewers suggested that the clinics may potentially have actually created demand by medicalising minor problems that might otherwise have been dealt with at home. However, as there was no data collected on the reasons for using the clinics in any of the studies, this suggestion could not be supported with evidence. It was interesting to note that the review contrasted the clinics with successful examples of

"nurse-managed settings in New Zealand and the United States [that] have been carefully planned to meet underserved areas and identified populations who experience barriers to accessing primary health due to financial, geographical or cultural reasons." (Desborough et al 2012, p. 261).

A similarly untargeted project in Canberra also proved to have relatively little impact (Parker et al 2012). A free, nurse-led primary care walk-in centre in Canberra was set up adjacent to the Canberra Hospital to address a general shortage of primary care services in Canberra. It did not specifically target low income or disadvantaged populations and was separate from but on the same site as an after hours GP-led primary care centre. An evaluation of the walk-in centre was conducted in May 2011, one year after the centre's inception. The evaluation was based on face-to-face interviews with "key stakeholders", seventeen health professionals who were purposively selected as having an expressed interest in the walk-in centre. While the interviewees were generally supportive of the walk-in centre's concept, there were many areas that needed addressing. These included the lack of an information system that was integrated with other parts of the health sector, the scope of practice for the nurse practitioners, which limited what they were able to achieve, education and training needs, particularly ongoing professional development for nurses, and the need to improve public awareness of the scope of practice of the centre in relation to general practice. Some stakeholders believed the funding would have been more usefully invested in general practice. This study did not contact clinic users, or supply any details on the health need, socio-economic status, or demographics of those who

attended the centre. There was also no information given as to why the nurse and GP centres ran separately instead of together.

More successful was a nurse-led clinic that focused on improving immunisation status among children and young people in a disadvantaged population in Hawaii (Niederhauser et al 2007). A health service for disadvantaged people (70% of patients at or below federal poverty level) started a walk-in vaccination clinic open to all children and young people up to 21 years, regardless of insurance status, immigration status, or nationality. The intervention was well planned and developed in consultation with parents of children who were not fully immunised, and then promoted through the community and schools in the area before being implemented. The clinic was open two evenings per week and on Saturday mornings, hours which had been suggested as the most convenient for the target population. All children were assessed by a nurse practitioner and follow-up needs addressed such as medical appointments, physical examinations, dental referrals, social service referral and behavioural health services. Once the child had received their vaccinations, the parents were given a personalised reminder calendar with a digital photo of their child, brief information about the importance of vaccinations, and the clinic hours. After the clinic had been running for seven months an evaluation was carried out. In this time, a total of 351 clients visited the clinic and 774 immunisations were administered. Two thirds of the people who attended had not previously been members of the health service and many became regular patients. User satisfaction was high, and numbers using the clinic grew each month as word of mouth spread about its availability, and physicians in the area also began to refer patients. Up-todate immunisation status for those children and young people who attended aged between 6 months to 21 years increased from 41% pre-intervention to 65% postintervention. There were significant improvements in immunisation status in all ethnic groups except for Hawaiian/part Hawaiian which did however show a positive trend. A surprise finding from this study was the number of adolescents and young people over 12 years who accessed the clinic independently and who appeared to have been reached by the promotion in schools. The authors noted that although the lack of a comparison group was a limitation of their study, they believed that by simply providing a walk-in "all-comers" clinic at times and in a location that was accessible for families and young people, ethnically and racially diverse and poor children gained access to immunisations.

Finally, in the examples of nurse-led services is the report of the lessons learned from community-academic partnership to develop and implement a clinic in an underserved rural area of Indiana (Krothe et al 2000). The area had high needs, with many residents being uninsured or under-insured and there were higher than average rates of child abuse and neglect, deaths due to cerebrovascular disease, adolescent pregnancy, and adolescent suicide. The clinic had a dual purpose; firstly to provide disease prevention and health promotion services to country residents of all ages who had financial, geographical and cultural barriers that made it difficult for them to access health care, and secondly, to serve as an educational practice setting for Indiana University nursing students. The clinic was initially open for three hours per week at two school sites from 4pm-7pm, hours which had been found to best meet the needs of residents. In the third year of operation hours were extended to the high school site one afternoon a week for students, and one evening for all residents. Services included screening, health education for disease prevention and health

promotion, primary care services and referrals to other health and social service providers. The clinic was staffed by a community health nurse and two community health workers, as well as nursing students under the supervision of a faculty member from the University. Students were primarily engaged in designing and running health promotion for school students and other community groups. The authors noted that the application of the community development model presented many challenges: the difficulty of gaining trust in a community that was suspicious of outsiders; the length of time it took to engage the community and implement the project; the need to understand and work within local power dynamics before any progress could be made; and the tension between community expectations and the data-based outcome objectives that were needed to satisfy the funders that gains in health status had been made. There was also tensions for the academic staff between career demands and the commitment they had made to working in the field. However, it was an achievement that the clinic created a service where none had previously existed, and after the first three years the project was scaled up and additional funding sourced from state authorities to provide a full community health centre in the county.

#### Whānau Ora

No review of approaches to increase access to health care and reduce disparities in New Zealand would be complete without mentioning Whānau Ora. Whānau Ora aims to deliver integrated health and social services to families in need, focusing on whānau<sup>11</sup> as a whole rather than individuals and their problems. It specifically works at decreasing disparities in health and socioeconomic status between Māori and non-Māori. The whānau ora approach is an inclusive and culturally anchored approach based on a Māori worldview of health which assumes that changes in the wellbeing of an individual can be brought about by focusing on the whānau, or family collective (Boulton et al 2013; Taskforce on Whānau Centred Initiatives 2010). Whānau Ora is not a new concept for Māori; many Māori organisations have already been using this model but have found difficulties in being able to deliver a service that operates on whānau concepts but within a contract that focuses on Western concepts of disease (Boulton et al, 2013).

Boulton et al (2013) in their article on the challenges and opportunities of Whānau ora comment that the approach has the potential to radically transform the way health and social services are delivered to some of New Zealand's most vulnerable populations. However, they emphasise that it will be a major challenge for this "unique and innovative policy" (p. 30) to attain an overall improvement in health and well-being outcomes that are both meaningful at community and at central government level.

There are however, some promising results. A recent report (Ministry of Health 2013) measured the performance of general practices in whānau ora collectives against eleven indicators that link to major causes of morbidity and mortality for Māori. Compared to the previous year, improvements were made in four of the indicators: smoking cessation advice up 29.2%; recording of CVD risk up 17.5%; flu vaccination of those 65+ up 6%; and diabetes patient review up 3.8%. Moreover, smoking cessation advice and flu vaccination indicators exceeded the results of the

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 $<sup>^{11}</sup>$  The definition of whānau is discussed in detail in the Taskforce Report (2009 , p. 12) referred to in this paragraph.

national sample.<sup>12</sup> The report did not comment further on the significance of these results, but noted that and as has been noted by Freeman (2002, p. 132) indicators do not necessarily measure performance against the overall objectives are need to be interpreted 13), indicators are a limited way of measuring and the mean fees for enrolled patients in the whānau ora sample continued to be about half those charged in the national sample across all age groups. These lower fees are maintained partly through higher funding received by the Whānau ora sample, and the funding available through the very low cost access scheme available to primary health organisations and their practices if they agree to offer and maintain very low fees to their enrolled population for standard consultations.

## Youth specific primary care services

Youth access to primary care is known to be problematic internationally. Cost, concerns about confidentiality, not having the time and means to get to services, and not knowing what services are available are all barriers. They apply especially to older adolescents and young people who are making their decisions about health care independently from their parents (Hegarty et al 2013; DiClemente et al 2012). Craig et al (2013) in their discussion of models of primary health care delivery for young people note that although most young people in New Zealand have good health, 16.8% of those in the Youth'07 health survey reported being unable to access health care when they needed it. Sexual and reproductive health issues were of particular importance, with injuries, mental health issues, infectious and respiratory diseases also being key issues. The three most usual models of primary care available to young people are general practitioners, school-based health services, and youth specific health services, sometimes known as One Stop Shops. Craig et al (2013) review all three models of care and discuss New Zealand and international examples and evidence of their effectiveness. Most notable among the New Zealand literature reviewed was the evaluation of the Achievement in Multi-Cultural High Schools Initiative (AIMHI) which was implemented in some of the most disadvantaged schools in Auckland and Porirua (Ministry of Health 2009). The initiative focused on improving health and social service support for students and reducing barriers to learning. The evaluation found that:

- The provision of a student support service significantly increased access to health and social services
- Students and staff expressed increasingly positive views of the service and their willingness to use it over time
- Compared with their peers in other decile 1 schools, academic achievement and retention levels were higher, and truancy lower
- Teachers no longer had to attempt to deal with health issues for which they were ill equipped and were able to concentrate better on teaching
- The service supported the school's ability to provide the health education syllabus more fully.

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<sup>&</sup>lt;sup>12</sup> Freeman (2002) cautions that indicators should on ly be used carefully as they can have negative consequences unless they are treated as clues to performance, discussed and interpreted in the light of local contexts (p. 134).

The document by Craig et al (2013) is a comprehensive and recent summary of the national and international evidence. The main points are summarised below and there is more detail in the full report. However, apart from the AIMHI evaluations outlined above, it does not necessarily focus on access for the most disadvantaged groups but rather adolescent preferences for particular types of service. The review concluded that:

- Many young people express a preference for youth specific services but for
  most the first point of contact remains the general practitioner. However,
  young people use a variety of services including school health clinics, family
  planning and youth One Stop Shops. The choice of service depends on
  availability and the nature of the health concern at the time.
- There is insufficient evidence in the available literature to prefer one model of service delivery over another. Different models may better meet the needs of different groups of young people at different stages of their development. For example, school based services are valued by students but are inaccessible to young people who are not enrolled in school.
- General practitioners tend to be seen as appropriate by young people for injuries and simple acute conditions, but youth-focused services are preferred for confidential matters of reproductive health or addictions.
- Overarching frameworks for school health services and youth specific services are lacking and the delivery is uneven across the different DHBs. Stable ongoing funding remains a particular problem for youth specific services. (Craig et al 2013, p. 326-327)

#### **Discussion**

It can be seen from the above overview that there is a spectrum of approaches to increasing access to primary care for disadvantaged populations. At one end, is the navigator model that seeks out individuals or families and works with them on a personal level to reduce barriers to attending existing services; at the other is the reconfiguration of services to make them a more sensitive fit to the needs of the target group (such as Whānau ora and the youth One Stop Shops). However, all of the approaches, whatever the primary emphasis, include something of both of these aspects in various configurations. The navigator services need an appropriate service to refer their contacts to, and the service models need to promote their availability and features to the target community.

There is clearly a great deal of overlap between the various models. The community health worker and navigator roles have much in common, but both are vaguely defined. The terms have each been used to cover both formal and informal, paid and unpaid, lay and professional roles in various interventions. Nurse-led interventions are more formally defined as they are carried out by qualified health professionals. However, some of the navigation and community health worker examples used qualified nurses and social workers. Because of this fluidity of the roles across the literature and the variability of functions they perform, it would appear that there can be no definite conclusion about the superiority of one model over another. It is possible, however, to identify several major factors from the literature that have been associated with increased access for disadvantaged groups:

- Initiatives need to be targeted to a particular population with high needs. For
  example, the interventions in Hawaii and Hawkes Bay described above had
  considerable success, whereas the untargeted clinics in Canberra and the UK
  did not.
- Successful interventions need to be carefully planned, sufficiently resourced and well promoted both to the target group and to the relevant sections of the health and social care sectors.
- It does not appear to be of great importance whether interventions are directed generally across all health issues in a particular population group or more focused on one particular high health need in the target population, such as child vaccination, asthma, or diabetes. The more focused interventions also worked well in providing an entry point to more general health services for those who were not using them.
- Wherever possible, members of the target community who have similar cultural backgrounds and life experiences should be the front line workers, backed up with sufficiently well resourced and appropriate professional services to which they can refer those they contact.
- Locations and hours of service that suit the target community are consistently reported to have been a successful feature across many studies. These are not necessarily the traditional business hours of opening. Evenings and weekend hours have been popular.
- In urban areas where services exist but are not being accessed, or not accessed enough, the navigator/CHW role appears to be a valuable means of increasing access among disadvantaged populations.
- Nurse-led interventions appear necessary in remote or thinly populated areas
  where no previous services existed. In such an environment (for example, the
  initiatives in Reporoa and Reefton) services need to be run by health
  professionals who can operate safely where back-up may be some hours away.
  It may, however, also be appropriate to have lay community workers under
  supervision in some roles.

The literature also highlights issues which are still developing but which would need to be addressed before implementing any intervention:

- Lack of clear definitions or frameworks: Before implementing any intervention that involves navigators/CHWs or any other type of lay health worker it would seem critical to define the role and its scope. This does, however, need to be flexible enough to allow those in the role to address any barriers experienced by the target community without being limited by rigid protocols or "no-go" areas.
- Measuring outcomes: how success will be measured needs to be decided at the outset. It is clearly easier to measure the success of a very defined intervention (for example, number of children fully immunised) than a more general intervention that aims to reduce overall discrepancies in access to health care. The choice of particular indicators, while useful, does not capture the full extent of what a service is achieving. Moreover, working to meet data-based objectives may conflict with the wider expectations of the community being served.

- Finding the right people in the target community: suitable individuals who are willing and able to become navigators or community health workers have been described as "people of influence" or "natural helpers" who have shared life experiences with their community and have a passion for improving their community's health and social conditions. However, the literature is almost entirely silent on how these individuals in the target communities might be identified.
- Training and professional development: the two broad approaches are *either* to identify and train community members with no prior experience, *or* the reverse approach, to locate people with appropriate skills who have the required links and life experience. Given the current paucity of Māori and Pacific health professionals with the required experience noted in some of the New Zealand literature, it seems that these approaches may be complementary. Once in the role, however, a professional development path leading to qualifications for those who are initially untrained, would be necessary and would assist in boosting the appropriately skilled workforce as well as potentially inspiring other members of the target community to do the same. Note that the perception that the Partnership Community Workers were unqualified appeared to be a barrier to their acceptance by other health professionals.
- Supervision of the navigator/CHW role: in some examples, community
  members who have not previously held a professional position needed
  intensive guidance and supervision to start with. Issues of time-keeping and
  inappropriate dress were identified in some of the US studies, as well as poor
  choices in supervisors who were uncommitted to the intervention and lacked
  an understanding of the role. The increased workload of those who are doing
  the supervision needs to be recognised by their management.
- Payment and caseload: it is clear that once a community member takes on the
  role of navigator or CHW and are good at what they do, they can easily
  become overloaded and burnt out. This has particularly happened where
  community members were employed for a few hours per week and were paid
  only a small stipend for expenses. Some idea of caseloads related to the scope
  of particular roles can be derived from the literature by comparing the
  population served with the number of positions and the hours worked.
- Buy-in from the wider health sector: tensions between different sections of the health sector can compromise even the most excellent work in the community. Failure to achieve buy-in from some general practices, for example, was highlighted as an issue at least initially in the PCW evaluation and in some of the New Zealand nurse-led innovations. Some of the most successful interventions in the international literature were run from a health centre base where the community health workers or navigators returned frequently for training, reporting, and following up on referrals. This had the advantage of constant contact with the health service to which community members were being referred. However, the placement of Partnership Community Workers in community organisations was considered a strength in the PCW evaluation. It may be that either way works as well as long as all services are engaged in the project and equally committed to it
- Resourcing: employing lay health workers whether navigators or community health workers is not an inexpensive option. Thought needs to be given to

recruiting, training, promoting, resourcing and sustainability before implementing any programme.

## **Concluding comments**

There are numerous examples of initiatives to improve access to primary care that have reported their experience with what works and what does not, including many implemented in this country. Indeed, it would appear that the New Zealand initiatives are as well developed as anything undertaken internationally.

The successful outcomes reported, however, have mostly been only the beginning of addressing some of the issues in a particular health area or for a particular population group rather than reducing inequitable access in a more comprehensive way. There is also little evidence of initiatives that were sustained over a long period and therefore might have been in a position to measure whether improved access had also led to reducing disparities in overall health status in a particular population.

In spite of this caveat, there is fairly good evidence that well-chosen navigators and/or community health workers can improve access to primary care for a disadvantaged population with which they share links of culture and experience. However, they need to be backed up with high-quality, appropriate services to which they can refer people, and sufficiently supported by a well-planned and resourced programme that has addressed the areas of difficulty noted above.

It is clear that all the approaches described in this report have their own merits and have complementary advantages in improving access to primary health care. It may be that attacking the problem of inequitable access to primary care from several or all of these different angles may in the end be the most useful way ahead.

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