

## Developing Care in the Community

### Introduction, Definitions and Concepts

It is difficult to define clearly what community healthcare is and what services we should develop. There are some definitions of what is community health care, as given by different agencies and governments below. In addition, in Table 1, are examples of such services in the United Kingdom and Australia.

*“Community health services cover an extensive and diverse range of activities and are difficult to define. Services are delivered in a wide range of settings – including in people’s own homes as well as in community clinics, community centres and schools – so are less visible than services delivered in hospitals and GP surgeries.”* King's Fund UK 2019<sup>1</sup>.

*“Community health is a multi-sector and multi-disciplinary collaborative enterprise that uses public health science, evidence-based strategies, and other approaches to engage and work with communities, in a culturally appropriate manner, to optimize the health and quality of life of all persons who live, work, or are otherwise active in a defined community or communities.”* Goodmana, Bunnellc, Posneraa. Centers for Disease Control and Prevention, USA 2014<sup>2</sup>.

Community-based services include *“any form of assistance, support and care that enables people to overcome or manage whatever condition, disability or set of life circumstances they face. ‘Community-based’ refers to the idea that vulnerable people should live alongside ‘ordinary’ people in their local communities, rather than be segregated. This type of care tends to be seen as the best setting in which to empower the user to participate in society and to take control of his/her own life.”* European Expert Group on the Transition from Institutional to Community-based Care 2019<sup>3</sup>.

*“Definitions in the area of “community health services” are confusing: there is no consistent global usage of the term .... community-based health-care services (CBHS) is taken to mean: ‘all services provided by people who spend a substantial part of their working time outside a health facility, discharging their services at the individual, family or community level, as well as primary health care services provided in small local health facilities. The exact boundaries of the definition will differ from country to country’.”* World Health Organization 2016<sup>4</sup>.

Table 1: Comparison Care in the Community (community health services or programmes) in the UK & Australia<sup>1,5,6</sup>

Examples of NHS community health services (Source: The Kings Fund, UK)	Examples of Australian Community Health Services (Source: DoH, Victoria, Australia)
Health visiting	Child Health Services
School nursing	Chronic Disease Management (plus Self-Management)
Sexual health services	Dental Health Services
Child health services	Disability Services
Community occupational therapy	Drug And Alcohol Services
Community paediatric clinics	Family Planning
Community palliative care	Refugee Health
Community physiotherapy	Health Promotion
Community podiatry	Medical Services
Community speech and language therapy	Home And Community Care Services
District nursing	Mental Health Services
Falls services	Post-Acute Care Services
Intermediate care	Language services
Specialist nurses (eg, diabetes, heart failure, incontinence)	Innovative Health Service for Homeless Youth (IHSHY)
Wheelchair services	Telephone Counselling
	National Diabetes Services
	Community health nurses in Sexual Assault

The European definition is good but none are adequate. It must be recognised that self-care is a vital component of community care. Community care is not to take away the independence and self-care of an individual but to complement it; as Ivan Illich so eloquently described it, *“Effective health care depends on self-care; this fact is currently heralded as if it were a discovery”*. It is also difficult to decide as to where to position community care in the health system. Is it to be placed within primary care or is it an entity of its own? I believe that putting it within the primary care services of the Ministry of Health (MOH) would overburden an existing, already overburdened system. MOH primary care services have been expanded extensively with little injection of resources. In Figure 1 I have tried, in a simple form, to illustrate the different sectors and locations of healthcare. Community Care by definition must be located in the community. This means in homes of individuals, in NGOs located in the community, or perhaps in service centres that are located close to where people live. Easy access is a hallmark of community care. The difficulty would be how to coordinate and integrate it.

Hospital				Health		Community		
ICU	Ward	Specialist Clinic	District Hospital	OPD	Health Centre	Centre	NGO	Home

Figure 1: Distribution of healthcare service by sector

**What are the Needs and Services to be Developed in Malaysia?**

The key problem with developing services in the community is the **current failing health system**. The Malaysian Health System has been failing for some time and is on a steady decline for more than 2 decades. Although we can suggest need and services, these can only be adequately developed if we revamp the existing health services totally. Starting from the ground up, all over again, may be necessary as no cosmetic change, rebranding or reorganisation will work.

Table 2 below describes in summary a list of services that have been developed or should be developed in terms of community care in Malaysia (not exhaustive). It is important to recognise that no single agency can meet these needs and that service provision will take time to develop. It is important to stress here again that reliance must be built into the community for self-care and programmes should not just be developed for the delivery of care to individuals but it is equally important to enable and empower individuals and communities to care for themselves.

Table 2: Services that have been developed or should be developed in terms of Community Care in Malaysia

Community Care/Health Services	Comments/Explanations
Antenatal and Postnatal homecare services	Home visits by MOH public health nurses is well established and post-natal visits are mandatory (weaker in urban settings).
Child Health services	Home visits by MOH public health nurses are well established for children immediately after birth but not adequate for later years (weaker in urban settings).
School Health services	MOH has an established school health programme but this does not reach 30% of children who are in tahfiz or home schools. In addition, support for children in school with developmental problems is weak.
Dental Health services	Extensive School Dental Service under MOH reaching most government school children using mobile dental teams/clinics (poor coverage of tahfiz & home schools).
Sexual Health services (including Family Planning)	MOH provides family planning support at all health clinics. LPPKN has centers in all states and 49 Klinik Nur Sejahtera. Private sector also supports family planning. Contraceptive support for adolescents however is still limited.

Adolescent services (mental health, guidance, sexuality, etc) including online and telephone support	MOH has a 2015, National Adolescent Health Plan of Action 2015-2020. Majority of adolescent services are based under family health services in MOH health clinics. MOH has PROSTAR (Program Sihat Tanpa AIDS untuk Remaja) as a community engagement programme since 1996. Outreach of these services into the community is limited. National Population & Family Development Board (LPPKN) has kafe@TEEN centres (14). Ideally adolescent services should be based where access is easy (drop in centres at shopping complexes).
Disability services – children and adults	Currently most community disability services are by NGOs. MOH is better in rural communities and work with Welfare department's CBRs (limited functionality).
Elderly – especially related to self-help, dementia, disability, stroke, etc	Domiciliary Healthcare Service by MOH introduced 2014 (based in 160 health clinics), served 8,302 patients, 70% elderly (up to 2018) <sup>8</sup> . Limited services, mainly clinic based. Welfare Department has 10 Rumah Sri Kenangan (old folks homes) & 2 Rumah Ehsan (older person with chronic illnesses). NGOs have centres. Privately registered centres: 244 under Care Centre Act & 16 nursing homes under Private Healthcare Facilities & Services Act. Unregistered nursing homes employing foreign workers uncertain. Large need for home care services.
Palliative care and End-of-life services	Palliative care largely done by NGOs but not widespread. MOH services mainly hospital based with some home visiting.
Chronic Disease Management (plus Self-Management)	Specialist home nurses (eg, diabetes, asthma, epilepsy, etc) and family support group community services required (some NGOs).
Post-Acute Care services (including wound care)	There is a need to develop post-trauma wound care services that are home-based. Currently these are hospital or clinic-based.
Non-communicable Diseases (NCDs) detection & prevention	"Komuniti Sihat Perkasa Negara" (KOSPEN) Programme – from 2014 to 2019, 974 KOSPEN localities established, 36,000 volunteers trained, screened 821,600 people for NCD risk factors <sup>8</sup> . No audit of effectiveness.
Mental Health services	The MOH SOP on psychiatry <sup>9</sup> has 'Community Mental Health Centers' and a MENTARI programme to improve outreach and re-integration of people with mental health problems. But what proportion of the population it reaches and its functioning is uncertain. Need to work on prevention.
Drug Addiction, Smoking cessation and Alcohol services	Significant proportion of population is addicted to drugs, cigarettes or alcohol. Decriminalisation is effective first step but we need the supportive resources to enable the community to move away from addiction to healthier pursuits.
Post Emotional Trauma services (abuse, rape, miscarriage, etc)	We require routine post emotional trauma counselling and support services. Currently predominately by NGOs and hospital based services.
Respite Care for caregivers	Almost non-existent (2 initiatives).
Service for Homeless	Welfare Dept. has 2 Desa Bina Diri (homes for the homeless). Multiple NGOs (KL alone has 14) in various cities providing food & healthcare <sup>10</sup> .
Refugee Health (& Asylum-seekers)	Financial constraints and language issues key challenges.
Health Promotion & Prevention	Focus on Wellness ( <b>the largest area</b> ) e.g. eating, weight, activity, injury prevention, etc.

Current established services by MOH are better for rural communities and semi-urban environments. They do poorly when it comes to larger cities with inner city slums, migrant and immigrant workers. In addition indigenous people groups are also not adequately served. The **most poorly served communities**, even for basic antenatal, postnatal, child health services are the indigenous communities, followed by refugees, economic immigrant populations and local migrant to the city (urban communities). In addition MOH community initiatives have rarely been audited seriously in terms of outcome and effectiveness.

There is also the challenge of mushrooming private and alternative care services. Healthcare is now viewed as a very lucrative business. There is a tendency to try and make patients addicted to the needs of healthcare and hence health promotion and wellness are not activities that the private sector would regularly be involved in (a conflict of interest). Some individuals have capitalised on this and use mobile applications or web based applications to connect communities and individuals with service providers. Although this may be a novel way to enhance community care it still may not provide the necessary comprehensive service that we are looking for and are predominantly curative based. Alternative and complementary services have also grown extensively and have, at times, done better than 'mainstream' medicine in meeting the needs of the community.

### **Who should do it? How can it be achieved? Manpower Needs**

Establishing Community Care Services will require some major initiatives and changes.

#### Mobile services (buses/vehicles)

It is important to recognise that much of these services need to be mobile and not building-based. It's important not to invest too much money in more buildings but invest money in manpower and mobility. It may be ideal to develop buses or vehicles that can provide services and these can be used to for delivery of and access to care in different geographical areas (buses can be redesigned to have examination areas, medication dispensing, basic investigations).

#### Decentralisation of services

Another key point is the need to decentralise services. There is an excessive pooling of healthcare expertise in major cities especially KL. We must be committed to decongest manpower and enable the services to go up-stream to the community.

#### Change in training of HCPs

There will be a need to change the fundamental training of healthcare professionals in medical schools as well as in allied health facilities. If doctors, nurses and other professionals are trained in a curative manner and train to work in institutions, they will not be able to function in the community.

#### Trans-disciplinary therapists

There is a need to invest in the development/training of trans-disciplinary therapists. Individuals who do not perform just one function but can do many roles. The best example of this would be a person who can work with the disabled in speech, physio, occupational and education therapy.

#### Using NGOs better

There should be an increased utilisation of non-governmental organisations in the delivery of care to the community. NGOs are better at working in the community and have less bureaucracy and obstacles in working. They can enable healthcare professionals to work better in the community. Central government should consider funding community-based NGOs better.

#### Empowering of the community for self-care and training carers

**The cornerstone for developing community care will be enabling and empowering the community to care for themselves.** This is the weakest link in the development of services. It is not a pushing of care to the community but a growing of the capacity of the community to better deal with their own health. To enable this we may have to really look at how and what we teach our children in our schools about health. As well as develop a whole cadre of **empowering community workers** who can galvanise the community and work towards wellness. **We need to move away from a mind-set of delivery of healthcare to the community and work towards the development of capability within the community for self-care.**

**Manpower**

We currently have 3-4 times more hospital beds and physicians (doctors) per 1,000 people than we have community health workers (public health nurses), which is of concern (see Table 3). While manpower numbers are hard to determine, the minimum that we require for every thousand population are:

- five community health workers (nursing based training)
- five trans-disciplinary workers (disability, elderly based training)
- two-three counsellors/psychology trained persons (adolescent, mental health)

In addition we require 1-2 specialised mobile rapid response teams than can deal with more severe problems for every thousand population. **The primary role of these staff would be to enable community self-care and wellness. The key would be to harness the enormous potential of the community itself to meet its own needs.** The government’s role would be to fund such initiatives and put more purchasing power into the hands of the community.

There is a huge data/research need to determine real manpower requirements as well as how to make community transformations happen. We require evidence to support community self-care as cost-effective and has good outcomes.

Table 3: Global Health Workforce Statistics, OECD, supplemented by country data<sup>11</sup>

Category (per 1,000 population)	Malaysia	Singapore
Community health workers	0.4 (2010 data)	0.5 (2016 data)
Hospital beds	1.9 (2015 data)	2.4 (2015 data)
Physicians	1.5 (2015 data)	2.3 (2016 data)

**Key Challenges & Direction**

The key challenge in supporting community health is the social determinants of health. The prevailing **poverty of 30-40% of the general population means that any initiatives to support the community will be difficult to implement and possibly fail.** It will be hard to build community resilience and self-care when you need to worry about daily needs. The urban poverty line income (PLI) needs a realistic revision and strong measures to support financial needs of the lower income segment of the population are critical.

The challenges we will face in growing and establishing community care will be the difficulty in integrating the different health sectors and co-ordinating continuity of care between the health sectors<sup>12</sup>. In addition there will be the politics and territorialism that comes from different disciplines and specialities. There will be some resistance from healthcare professionals who are not keen to work in the community, especially specialists. There will be loud voices calling for more institutional, hospital-based care that manages disease, rather than community-based care.

We have developed a society that is addicted to doctors and specialist and disease treatment. It will be very hard to reverse this overnight, especially in the private sector. Wellness and empowerment of communities will require a change in mind-sets of not just professionals but also the public. The movement we are speaking about is best illustrated by a diagram from Tom Ferguson on transformation of our healthcare from a doctor focused one to a person-centred care.

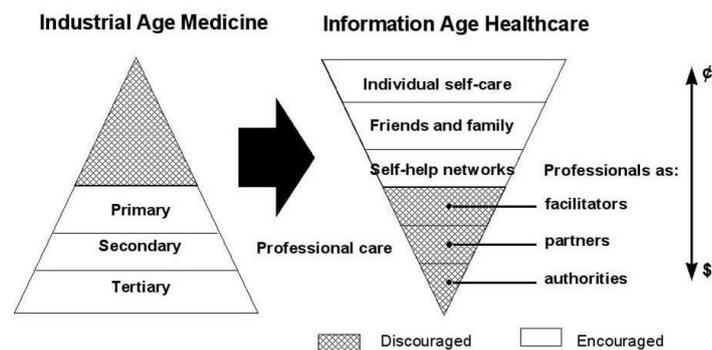


Figure 2: Tom Ferguson: Transformation from industrial age medicine to information age healthcare, 1995<sup>13</sup>

The key differences from our current healthcare system to one which focuses on community care are<sup>14</sup>

- A movement from a disease-centred care to a person-centred care.
- A movement from a focus on intermittent, episodic illness to a focus of continuous life-long health.
- A movement from limited consultation to one of enduring personal relationships and integrated care.
- A movement from the community as consumers of healthcare to one where the community are partners in managing their own health.

While we may look to government to provide strong leadership, direction & funding to stimulate community care, the real transforming movement might be from the community itself – a grassroots, grounds-up service development.

## Conclusion

In a sense medicine is returning to its roots. Healthcare professionals were once embedded in & integrated with the community. They recognised the strengths of individuals to maintain their health. With time this relationship became fragmented & divorced, we moved to curative model. With the focus of developing care in the community, we now hope to return to a person-centred integrated care system, where the person & community are viewed as their own healer.

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### Key Issues

1. We have a failing health system.
2. Poverty is prevalent (social determinants of health) & must be dealt with if we want community care.
3. We don't really know how to harness the community to care for themselves.
4. Funding is required to make it happen.