Children's Access to Healthcare

Speaking for the Unspoken Needs of Children

and What we Can Do to Make it Better

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Prepared for
The Medico Legal Society of Malaysia
Speaking for the Unspoken
12 Feb 2022

Important Special Note

In general, we have a robust public health system that is accessible by the majority of communities and families in Malaysia with minimal or no payment. However, there are children who remain fragile and underserved; there are 'pockets' of children who lack adequate access to health services. This article outlines major areas where children in Malaysia still face limitations in access to healthcare and offers recommendations for improvement.

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Citation

Dato' Dr Amar-Singh HSS (2022). Children's Access to Healthcare: Speaking for the unspoken needs of children and what we can do to make it better. Medico Legal Society of Malaysia.

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Dedication

To the First Nation of the Orang Asli People of Malaysia on whose land I live.

Children's Access to Healthcare

Speaking For the Unspoken Needs of Children and What We Can Do to Make It Better

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Introduction

Internationally and locally a child is defined as 'a person under the age of 18 years' in the Child Act 2001 (revised 2016)[1] and Convention on the Rights of the Child[2]. Children and adolescents comprise about a third of the population of Malaysia (see Table 1).

Table 1: Population Data on Children in Malaysia, 2020

Age (years)	**Numbers in 1,000s**			**% of Total Population**
	Male	**Female**	**Total**	
0-4	1,313.2	1,229.0	2,542.2	7.8%
5-9	1,321.7	1,232.3	2,554.0	7.8%
10-14	1,288.8	1,215.3	2,504.1	7.7%
15-19	1,468.3	1,367.4	2,835.7	8.7%
Population of Children (Sub-Total)	**5,392.0**	**5,044.0**	**10,436.0**	**32.0%**
Total (all ages including adults)	16,805.6	15,851.7	32,657.3	100%

Source: Department of Statistics, Malaysia 2021[3].

Access to Health as a Right

The UN Convention on the Rights of the Child (UNCRC)[4] adopted in 1989 clearly states in Article 24 that it is the "*right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health*". It goes on to outline that it is the responsibility of governments to "***strive** to ensure that no child is deprived of his or her right of access to such health care services*". The use of the word "strive" implies a strong emphasis on doing the 'best you can', 'make great efforts to achieve', 'fight vigorously' to ensure this. This shows the importance placed on access to health and attainment of good health in children. Article 24 goes on to outline the provision of health services for children, the focus on reducing childhood mortality and the provision/access to education about child health, nutrition, prevention of injuries, etc. The Child Act 2001 (revised 2016) states in clause 17 that "*A child is in need of care and protection if the child needs to be examined, investigated or treated for the purpose of restoring or preserving his health*".

To ensure universal access to health for all children in Malaysia, we require a rights-based approach as outlined in the UNCRC.

[1] Laws of Malaysia, Act 611 Child Act 2001, incorporating all amendments up to January 1, 2006 https://www.kpwkm.gov.my/kpwkm/uploads/files/Dokumen/Akta/Akta%20kanak-kanak%20pindaan%202016.pdf
[2] Convention on the Rights of the Child. Adopted by the UN General Assembly Nov 1989. Acceded to by Malaysia in 1995. https://www.ohchr.org/en/professionalinterest/pages/crc.aspx
[3] Department of Statistics, Malaysia (2021). Population by Age Group, Sex and Ethnic Group, Malaysia. https://www.data.gov.my/data/ms_MY/dataset/population-by-age-group-sex-and-ethnic-group-malaysia
[4] Convention on the Rights of the Child. Adopted by the UN General Assembly Nov 1989. Acceded to by Malaysia in 1995. https://www.ohchr.org/en/professionalinterest/pages/crc.aspx

A Summary of Key MOH Child Services Data[5,6]

Important note: In general, we have a robust public health system that is accessible by the majority of communities and families in Malaysia. However, despite extensive progress in medical care and some improvement in human rights in Malaysia, there are children who remain fragile and underserved. There are 'pockets' of children who lack adequate access to health services. The 'inverse care law' (those who need health care the most are the ones least likely to get it) has worsened especially with extensive urbanisation. This brief article is to outline major areas where children in Malaysia still face limitations in access to healthcare and offers recommendations for improvement. I will not be covering the payment-based health services in the country (private hospitals/clinics and over the counter pharmacy sales)

As of 2019 and based on population according to age, 75.7% of children below 1 year, 47.4% of children 1 to 4 years and 24.8% pre-school children (5-6 years) received services through primary health clinics. There were 6,164,662 antenatal attendances, 488,603 postnatal attendances and 10,463,308 child attendances to maternal and child health clinics. Immunisation coverage for 2019 was reported as exceeding 95% for primary vaccination BCG (98.5%), DPT-IPV-HiB Dose 3 (96.9%), Hep B Dose 3 (95.9%) and MMR Dose 1 (95.6%). Uncertain if this immunization figure includes migrant, refugee and stateless children in the country.

School health services, comprising health education, screening, health appraisal, immunisation, treatment and referral, had a coverage of more than 98% for Year 1, Year 6 and Form 3 school children. School health immunisation includes vaccines; MR and DT for Year 1, HPV for girls in Year 1 and ATT for students in Form 3 - coverage for all vaccinations in school children was more than 95%. Most private schools using the MOE syllabus are covered and international schools need to apply for services. Some registered state religious schools (tahfiz schools) are covered but due to the limited number of school health teams the services are incomplete.

In 2019, adolescent population screening exceeded the annual target of 5% and reached 350,567 adolescents (6.5% of adolescent population). 11% had nutritional problems, 3.7% had risk-taking behaviours, 2.3% had physical health problems, 0.9% had sexual-reproductive health problems and 0.7% had mental health problems. New antenatal cases (teenage pregnancy) among adolescents registered in the MOH primary healthcare facilities showed a decline from 13,831 (2015) to 10,349 (2019). 40.2% were unmarried and 80.2% were no longer in school.

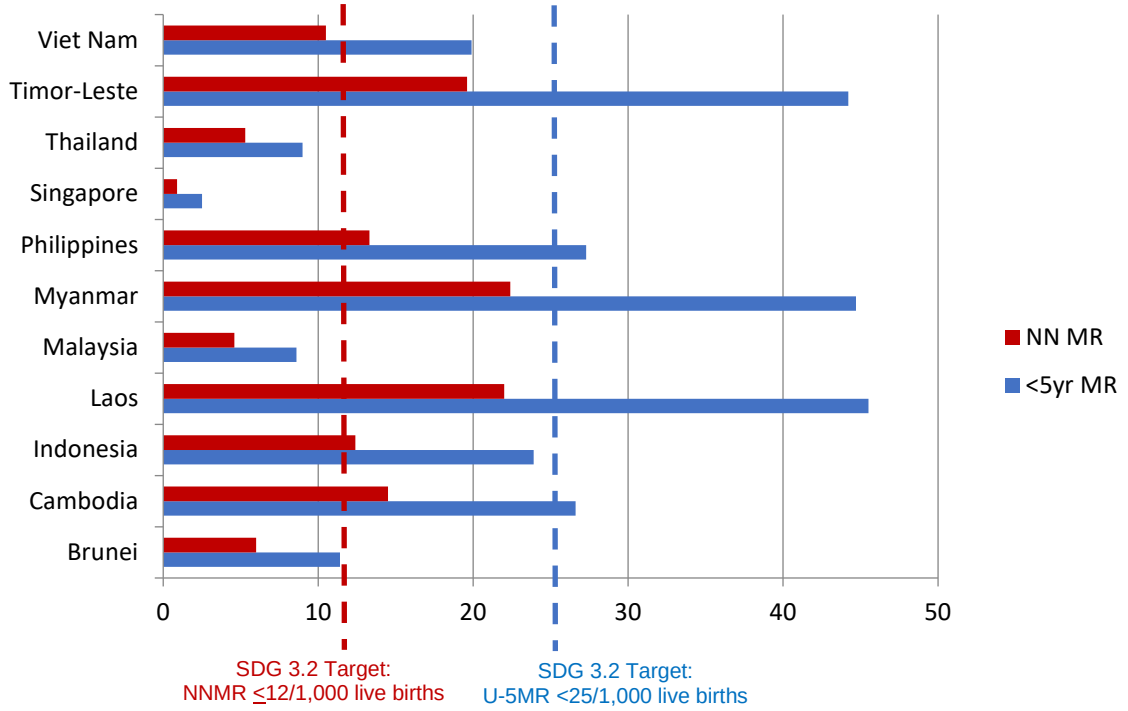
Utilisation of primary oral healthcare services in 2019 included 1,218,595 preschool, 2,890,267 primary school and 1,948,194 secondary school children.

Data for child specialist clinic visits and in-patient children's admissions are not made available from MOH. There is no data on services provided to children by university hospitals and the private sector (possibly 30% of the workload).

[5] MOH Health Facts 2020 (based on 2019 data).
https://www.moh.gov.my/moh/resources/Penerbitan/Penerbitan%20Utama/HEALTH%20FACTS/Health%20Facts%202020.pdf
[6] MOH Annual Report 2019.
https://www.moh.gov.my/moh/resources/Penerbitan/Penerbitan%20Utama/ANNUAL%20REPORT/LAPORAN%20TAHUNAN%20KKM%202019/mobile/index.html

The figure below shows under 5-year childhood death rates (and neonatal death rates) for Malaysia, compared to ASEAN nations. While Malaysia appears to have achieved SDG targets, we know that the **lack of disaggregated data** hides the situation in marginalised communities. Mortality rates are linked to social determinants of health (childhood mortality is related to family income). Governments rarely show disaggregated data, data broken down by detailed sub-categories (indigenous, marginalised groups and of level of income), and this is a glaring omission in SDG achievement. We can get some glimpse into this by using data on indigenous children as a proxy. For example, **using under-5 deaths in Malaysia for 2016 the age-specific mortality rate by ethnic group for Peninsular Malaysia indigenous children (Orang Asli) was 11 times that of major ethnic groups; while the mortality rate for indigenous ethnic groups in Sabah and Sarawak was 1.7 times that of major ethnic groups**. Indonesian and Myanmar residents under-5 age-specific mortality rates were 25x the national average.

Figure: Under Five and Neonatal Mortality Rates for South East Asian Countries, 2019[7]



Source: UNICEF database, updated September 2020

The subsequent discussion looks at key areas where children in Malaysia still face limitations in access to healthcare and are marginalised. Recommendations for improvement are offered.

The 'inverse care law':
those who need health care the most are the ones least likely to get it

[7] Amar-Singh HSS (2021). Why Children Need South East Asia to Achieve SDG 3 Goals: Successes and Challenges in Implementing SDG 3 in South East Asia. Royal College of Paediatrics and Child Health Conference. https://drive.google.com/file/d/1hSui4RWW8qoPay5iHZylK_Y-LdnfgUNY/view?usp=sharing

Recognition of All Children by Age with Provision of Appropriate Healthcare by the Ministry of Health

Despite the recognition by the Malaysian government that all persons under the age of 18 years are children (Child Act and the UNCRC), many government agencies and legislation deny this reality. The Ministry of Health (MOH) is long overdue in recognising that those aged 12-17 years are children. These children are usually admitted to adult wards; frighteningly and traumatically placed next to ill 50–70-year-old adults. They are also seen in adult-based clinics, often by individuals who lack adequate training in dealing with adolescents. The development of targeted and appropriate services for this ~15% adolescent population has been limited.

Services for children in general are not on par with services for adults. While adult curative speciality and intensive care services (ICU) have grown by leaps and bounds, services for children have only grown incrementally. ICU services for children are grossly inadequate. Some premature infants may not be offered care when beds are limited (this happens most days of the year, in most MOH hospitals).

Recommendations

Government policies must come in line with the laws of the nation. MOH policy must urgently change to accept the reality that children and adolescents need to be placed and seen in appropriate child-friendly health facilities and under the care of those trained for their needs. All hospitals must have adolescent wards and clinics manned by clinicians and staff trained in their care.

There is an urgent need to accelerate the development of tertiary speciality services for children and significantly grow PICU and NICU beds to meet acceptable norms.

Refugee Children in Detention

There is limited recent data on the health status of and access to healthcare for children in detention and refugees. Prior data suggest that "*child detainees in Malaysia are detained in unacceptable fetid conditions and are often placed in adult facilities by gender*"[8]. The United Nations High Commissioner for Refugees (UNHCR) has been denied access to all detainees (immigration detention centres) since August 2019. Civil Society Organisations (CSOs) are also not able to visit. We are aware from the media and other reports[9,10] that more than 1,000 refugee children are being held in detention, some without their parents or guardians present – a travesty - and one that further diminishes their access to health and services.

[8] Asylum Access Malaysia and the Asia Pacific Refugee Rights Network (2018). Malaysia Universal Periodic Review – 3rd Cycle. https://asylumaccess.org/wp-content/uploads/2018/04/AAM-APRRN-UPR-Submission-Malaysia_FINAL.pdf

[9] Emily Fishbein (2020). Lone children among hundreds in Malaysia immigration detention. Aljazeera https://www.aljazeera.com/news/2020/12/10/lone-children-among-hundreds-in-malaysia-immigration-detention

[10] Human Rights Commission of Malaysia (SUHAKAM) (2020). Annual report 2019. https://www.parlimen.gov.my/ipms/eps/2020-11-04/ST.88.2020%20-%20ST%2088.2020.pdf

As of end December 2021, there were 180,440 refugees and asylum-seekers registered with UNHCR in Malaysia. Of these, 46,170 were children below the age of 18 years[11]. Malaysia does not have a legal framework for refugees and is not a signatory to the UN Refugee Convention, hence they are detained as undocumented migrants. The immigration laws also do not conform to the Child Act and the UNCRC and do not appear to distinguish between children and adults. Hence children in detention have no access to education and we are uncertain about their health, nutrition and protection status. Children under 12 are held with adult women, while boys over 13 are held with adult men, which separates children from their families[12]. Anecdotal information from medical colleagues, who have been requested in an official capacity to visit immigration detention centres, describe less than ideal conditions and serious concern for the health and nutrition of children placed there.

Recommendations

The Child Act does not expressly mention refugee or migrant children, however the Act covers all children in Malaysia (including refugees), not just Malaysian children. We urgently need to move all children out of detention centres into safe shelters where they can have access to meaningful education, healthcare and protection.

Children should not be separated from their parents and families.

The UNHCR and CSOs should be accorded full access to all children in immigration detention centres and be allowed to support their health and nutritional needs.

Routine Healthcare for Migrant, Refugee and Stateless Children[13]

The polio outbreak in Sabah in 2019 highlighted the longstanding neglect and lack of provision of routine primary healthcare for migrant, refugee and stateless children[14]. The basic rights to healthcare for these children, as enshrined in the UNCRC, have not been upheld by the Malaysian government. These children do not receive routine primary immunisation, as well as growth and developmental monitoring, and health advice/education. Provision of primary immunisation to these children protects not only them but all Malaysian children (herd immunity).

There exist many barriers to these families accessing healthcare for their children, which include: fear of being deported, poverty, work mobility, language and the lack of respect and treatment received from health staff. Government-run public healthcare facilities are

[11] Figures at a Glance in Malaysia. UNHCR Malaysia. https://www.unhcr.org/en-my/figures-at-a-glance-in-malaysia.html
[12] Emily Fishbein (2020). Lone children among hundreds in Malaysia immigration detention. Aljazeera https://www.aljazeera.com/news/2020/12/10/lone-children-among-hundreds-in-malaysia-immigration-detention
[13] Asylum Access Malaysia and the Asia Pacific Refugee Rights Network (2018). Malaysia Universal Periodic Review – 3rd Cycle. https://asylumaccess.org/wp-content/uploads/2018/04/AAM-APRRN-UPR-Submission-Malaysia_FINAL.pdf
[14] Malaysiakini (2019). The arguments for mandatory vaccination in Malaysia. https://www.malaysiakini.com/letters/503048

accessible to 'foreigners', but at a much higher cost compared to Malaysian citizens; often out of the reach of most migrant, refugee and stateless families. Much of the current provision is ad hoc by CSOs or by government agencies when an outbreak occurs.

Healthcare for ill children who require hospitalisation or to see a specialist is even worse. While admission is possible for life threatening illnesses, guardians still have to pay high fees for hospitalisation, procedures and medications[15]; putting such healthcare out of the reach of many (admission deposits range from RM 500-1,200 depending on category of illness). Some who are admitted are denied a discharge until they can settle the bill. Currently various funding mechanisms are used to support these children, including CSO funding, ethnic/country based NGOs raising funds, public fund raising or collections by MOH staff. Note that the hospital director can waive ward charges. At discharge these children, even with chronic problems, are only given five days' worth of medication with no follow up. MOH guidelines require health staff to report all undocumented foreigners to the Immigration Department or Police (this happens even at the time of birth of a child).

Recommendations

We require legislation that guarantees all children living in Malaysia a right to health care, regardless of their legal status.

In line with the UNCRC Article 24, all children, regardless of status, should have universal access to health services, including hospitalisation, treatment of illness and rehabilitation of health. Prohibitive and expensive fees/charges should be removed.

There is a need for the government to respect the basic child rights in the UNCRC and provide routine, free primary health care and immunisation to all children in Malaysia, regardless of their status. No children should be denied basic immunisation or health access when necessary.

All children with chronic illnesses should be given appropriate health care and medication.

Migrant, refugee and stateless children/families need to be protected against arrest and detention when they seek healthcare at hospitals and clinics.

Supporting Children Who Live in Poverty (Focus on Inner City Poor and Sabah)

The new poverty line income (PLI), revised from RM980 to RM2,208, revealed that approximately 405,400 households (~1.2 million children) were living in poverty (national poverty rate 5.6%). This rate is debatable as some industrialised countries quote higher poverty rates than Malaysia. With the worsening conditions due to Covid-19, the Department of Statistics now quotes a national poverty rate of 8.4%, or 639,800 households living in poverty[16]. However, research by the Merdeka Centre October suggest that Covid-19 has

[15] MOH. Garis Panduan Pelaksanaan Perintah FI (Perubatan) (Kos Perkhidmatan) 2014. Circular (17)dlm.KKM-58/300/1-5. https://www.moh.gov.my/index.php/database_stores/attach_download/386/257

[16] Department of Statistics Malaysia (2021). https://www.dosm.gov.my/v1/index.php?r=column/cthemeByCat&cat=493&bul_id=VTNHRkdiZkFzenBNd1Y1dmg2UUlrZz09&menu_id=amVoWU54UTl0a21NWmdhMjFMMWcyZz09

pushed another 8-10% of the population into poverty[17]. Current conservative estimates suggest that 3-4 million children live in poverty in Malaysia.

The problem of poverty has been compounded by the sharp increases in the urban population in Malaysia - 75% of the nation in 2018, and estimated 80% in 2020[18] live in urban environments.

There is considerable research to show that poverty is a major barrier to accessing health care and health information[19]. But poverty in itself seriously undermines health through nutrition and poor living/environmental conditions. Governments rarely focus on the poor in their policies or the implementation or monitoring of health service strategies[20]. Covid-19 has significantly worsened childhood malnutrition and access to health care[21].

It needs to be recognised that private health services are out of the reach (not accessible) to the majority of poor families. Half the specialist human resources in the country are in the private sector[22]; they look after less than one third the health work burden. This takes expertise away from those who require it while providing more personalised care to those who can pay for it. There is also a disproportionate distribution of specialists; they tend to be located at major cities and on the west coast of Peninsular Malaysia. Hence, some regions in the country, for example Sabah, are poorly served outside major cities.

[17] Merdeka Centre (2020) https://www.channelnewsasia.com/cnainsider/poor-malaysia-cope-challenges-posed-covid-19-pandemic-poverty-692066
[18] United Nations Department of Economic and Social Affairs (Desa). UN World Urbanization Prospects 2018. https://population.un.org/wup/Publications/Files/WUP2018-Report.pdf
[19] The World Bank (2014). Poverty and Health https://www.worldbank.org/en/topic/health/brief/poverty-health
[20] Peters DH, Garg A, Bloom G, Walker DG, Brieger WR, Rahman MH. Poverty and access to health care in developing countries. Ann N Y Acad Sci. 2008;1136:161-71. doi: 10.1196/annals.1425.011. Epub 2007 Oct 22. PMID: 17954679.
[21] Amar-Singh HSS (Nov 2020; updated August 2021). Covid-19 and its Impact to Future Generations. Speaking for the Unspoken 2020: The Vulnerable Population and Covid-19. Medico-Legal Society of Malaysia. https://bit.ly/3hMc7Qq
[22] Ministry of Health, Malaysia (2021). Health Facts 2020 (based on 2019 data). http://vlib.moh.gov.my/cms/content.jsp?id=com.tms.cms.section.Section_2e813304-a0188549-d5315d00-719f1e10 and http://www.crc.gov.my/nhsi/wp-content/uploads/document/Distribuation_of_Clinical_Specialist_in_Malaysia.pdf

Recommendations[23]

Every child that continues to live in poverty is our nation's shame. If we are serious about improving child health and access to health for children in poverty, then we require radical changes in approach and not 'more of the same'. Our children need for us to achieve the UN's Sustainable Development Goals (SDGs) goals for ALL children, not as an average or for a portion of the community.

We can no longer rely on traditional and incremental approaches to improve health. We require a transformative approach that focuses on inclusive growth to achieve equality. The healthcare system must focus on marginalised communities. We require disaggregated data, broken down by detailed sub-categories (indigenous, marginalised groups, level of income, gender). We then need to map communities with high child mortality rates and focus sufficient resources on those with high rates. For this to happen we need compulsory death registration and mandated medical certification of deaths by law.

The government must be committed to adequately funding the healthcare system and allocate sufficient health resources to meet the need in the community.

Working on health alone will not result in the dramatic change in child mortality, morbidity or access to health care. For this to happen there is a need to end child poverty and hunger. The achievement of SDG 1 (end poverty) and SDG 2 (end hunger) will go a long way to help achieve SDG 3.

Reaching Indigenous Children[24,25]

(Note: Primarily focused on the Orang Asli)

Despite considerable improvement in health status of the general population in the past 50 years, Orang Asli health has not changed significantly and has deteriorated. The poverty rate for Orang Asli remains high at 80%; many remain as hard-core poor. Childhood malnutrition among Orang Asli children rates remains high; 60-70% are malnourished by 5-7 years of age. What is more worrying is that malnutrition rates are increasing in Orang Asli children. A recent study (2016) we conducted on all children aged below 2 years in Perak showed that >40% were malnourished by 2 years of age. The under 5 mortality rates for Orang Asli children were 11 times that of major ethnic groups in 2019. Some Orang Asli children have never been to school. More than 50% drop out of primary school. Of those that reach secondary schools only 30% complete secondary education. A tiny fraction reaches higher education. This perpetuates the cycle of poverty and limits health access.

[23] Amar-Singh HSS (2021). Why Children Need South East Asia to Achieve SDG 3 Goals: Successes and Challenges in Implementing SDG 3 in South East Asia. Royal College of Paediatrics and Child Health Conference. https://drive.google.com/file/d/1hSui4RWW8qoPay5iHZylK_Y-LdnfgUNY/view?usp=sharing

[24] Amar-Singh HSS (updated 2008). Mortality, Morbidity & Malnutrition In Orang Asli Children. https://hoag.moh.gov.my/images/pdf_folder/simposium/tujuh.pdf

[25] Amar-Singh HSS (2019). Malnutrition and Poverty among the Orang Asli (Indigenous) Children of Malaysia. Submission for UN Special Rapporteur on Extreme Poverty. https://www.ohchr.org/Documents/Issues/Poverty/VisitsContributions/Malaysia/IndigenousChildren.pdf

National advocacy with the Minister of Health, in 2008-2009, to transfer health services from the national Orang Asli government agency (JAKOA) to the Ministry of Health was successful after much pushing and allowed us to have improved health access to the community. However, access to health remains inconsistent for the community and depends on interest from local health authorities. The Orang Asli community in Malaysia is viewed by some as sub-human (proto-human); even some health staff seem disinterested and look down on the community. There is also mistrust of the health services by some Orang Asli communities.

MOH health services[26], targeting four weekly visits to the Orang Asli communities in remote villages using the Orang Asli Mobile Team, achieved 66.2% for 2019 (logistical issues, such as damaged roads, extreme weather conditions and damage to vehicles, limited travel). The Flying Doctor Services based at Kinta, Perak managed 41.6% of 173 planned flights to remote Orang Asli villages for 2019 (limited by weather conditions and technical issues with aircraft). In 2019 there were 641,880 Orang Asli visits to MOH health services for primary health care (including 102,960 antenatal, 6,332 postnatal, 129,314 child health and 110,626 home visits).

Recommendations

We need to employ culturally acceptable, appropriate and sensitive strategies for improving healthcare-seeking practices and behavioural change.

There is a need to develop community resilience in health and health access via the use of paid village health teams that are supported by MOH health services.

Orang Asli Mobile Teams and the Flying Doctor Services need to be strengthened with both human resources and finances to enable them to operate optimally.

Bringing every pregnant woman out, with the family, at 34-36 week of gestation, to await delivery in hospital and keeping them in the postnatal period with the child for 1-2 weeks before returning home, is critical to reducing perinatal and maternal mortality.

Establishing community re-feeding centres in villages and health facilities, that provide one protein rich meal to all children under 5 years of age, is the most successful upstream effort to reduce child mortality, but requires consistent funding and support.

[26] MOH Annual Report 2019. https://www.moh.gov.my/moh/resources/Penerbitan/Penerbitan%20Utama/ANNUAL%20REPORT/LAPORAN%20TAHUNAN%20KKM%202019/mobile/index.html

Children with Disabilities (including Rare Diseases)[27,28,29,30]

Data from international studies suggest that 10% of all children have developmental problems in the pre-school period and that, with age, the rate of detection increases to 15-17%[31]. This reality has yet to permeate the various government ministries, including MOH, in terms of provision of services.

Current health services for children with disabilities are better at assessment than intervention or education support. Rural communities have very limited access to any services. Vulnerable children in remote rural communities (Orang Asli, Penan, Interior of Sabah) have almost no access to services. Screening for children with disabilities is limited.

Local university medical student training curriculum for learning disabilities is almost non-existent. Most doctors have very limited knowledge and skills to evaluate children with disabilities and are not able to identify correctly children with learning disabilities. There is some growth in medical rehabilitation manpower but the delivery of services is still institutional based, adult and physical disability focused.

Covid-19 has worsened access to health care and services for children with disabilities. Most parents have reported a loss of progress made due to a loss of services. Children newly identified to have disabilities now have a later diagnosis, later therapy and hence poorer outcomes.

Children with Rare Diseases are currently often underdiagnosed, underserved with limited access to the already available therapeutic modalities internationally. Families are often hampered by a lack of access to information about the conditions[32]. While adults with chronic illnesses programmes receive large budgets (e.g. chronic renal disease and HIV), children with rare diseases have yet to have funding that is 'locked into the system'.

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[27] Amar-Singh HSS. Editorial: Meeting the Needs of Children with Disability in Malaysia. Med J Malaysia March 2008 Vol 63(1):1-3.
[28] Amar-Singh HSS. Screening & Diagnosing Learning Disabilities. SUHAKAM Forum on Children With Learning Disabilities, April 2013. KL, Malaysia.
[29] Amar-Singh HSS. Overview of initiatives & programmes, key challenges & obstacles to the full realisation of rights of children with disabilities in Malaysia. UNICEF round table discussion on children with disabilities, 3 June 2013, KL, Malaysia.
[30] Amar-Singh HSS, Lai-Thin Ng (2021). Future of Early Intervention Services in Malaysia. National Early Childhood Intervention Council. Malaysia. https://drive.google.com/file/d/1xs-J8x6TFq62-zq5jCX4PPQ3-Mt4xLq_/view?usp=sharing
[31] Centers for Disease Control and Prevention (CDC), US Department of Health & Human Services (2021). Developmental Disabilities. https://www.cdc.gov/ncbddd/developmentaldisabilities/features/increase-in-developmental-disabilities.html
[32] Shafie AA, Supian A, Ahmad Hassali MA, et al. Rare disease in Malaysia: Challenges and solutions. PLoS One. 2020;15(4):e0230850. Published 2020 Apr 2. doi:10.1371/journal.pone.0230850

Recommendations

MOH and other government agencies need to recognise that 15% of all children have a disability and plan, organise and budget accordingly. This means allocating sufficient human resources and funding to meet the need.

There is a need for MOH and CSOs to engage medical universities to dramatically improve the curriculum on recognition, assessment, therapy and community rehabilitation of children with disabilities.

The MOH needs to decentralise care to meet the disability needs of rural communities. We require outreach services for all rural, indigenous and poor urban communities.

MOH needs to have an official definition of rare diseases and advocate for sufficient resources to support these children and families.

Adolescents, Gender/Sexuality Issues and Mental Health

There are approximately 5.5 million adolescents in the country. The National Health and Morbidity Survey (NHMS) on adolescent health[33] showed significant health risk taking behaviour: 1:10 currently use alcohol, 1:5 of boys smoke (5% of girls), 1:25 have used drugs (3-4% currently on drugs) and 7-10% had sex. It also showed (based on validated questionnaires) a mental health crisis with 1:10 stressed, 1:5 depressed, and 11% of Form 1 students having suicidal ideation.

In principle, the MOH has a good National Adolescent Health Policy[34] that aims to empower adolescents to take responsibility for their own health with a good focus on mental and sexual health and risk-taking behaviours. However, in practice (from anecdotal data) there may be problems with staff on the ground who respond to teens from their religious or cultural perspectives (judgmental) and can limit access to services. This is especially so for sexuality related issues, contraception and transgender concerns.

It should be noted that part of the Sustainable Development Goal 3 (SDG3)[35] is to "*ensure universal access to sexual and reproductive health-care services, including for family planning, information and education…*" This is not available to all adolescents in the country, especially contraception.

There is a good school health programme with teams visiting schools but human resources are limited and have not grown in line with needs. Access to the highest risk teens is limited as outreach programmes to school dropouts and at-risk communities (street kids) is very limited and mainly confined to CSOs.

[33] Institute For Public Health, MOH (2018). National Health and Morbidity Survey (NHMS) 2017: Key Findings from the Adolescent Health and Nutrition Surveys.
https://iku.moh.gov.my/images/IKU/Document/REPORT/NHMS2017/NHMS2017Infographic.pdf
[34] Family Health Development Division, MOH (2022). National Adolescent Health Policy.
https://fh.moh.gov.my/v3/index.php/polisi
[35] United Nations: Department of Economic and Social Affairs - Sustainable Development
https://sdgs.un.org/2030agenda

It should be noted that adolescent's basic rights as patients in decision making is not supported in general as they are viewed as minors under the care of parents or guardians.

Recommendations

Adolescent's basic rights as patients must be strengthened to support their participation in medical decisions that relate to their own treatment.

We need to strengthen SDG3 targets and make available non-judgemental, universal access to sexual and reproductive health-care services, especially contraception.

MOH needs to strengthen human resources for the school health programme as well as develop outreach programmes targeting high risk teams (in partnership with CSOs).

Children in Prison and Institutional/Residential Care (Looked After Children)

Data on children in prison and their access to healthcare is limited. The number of children involved in crime in 2020 was 5,342 cases[36]. Malaysia Prison Department report (2015) and UNICEF/Royal Malaysia Police report (2013) show that 9,000 children were being held in prison. Children are also detained in Sekolah Tunas Bakti run by the Welfare Department, Henry Gurney Schools (2,353 children in 2016) and Juvenile Rehabilitation Centres operated by the Prisons Department[37].

There are also numerous children's homes run by the Welfare Department, children's homes and orphanages run by CSOs and religious bodies. In 2016, at 5,013 centres (Registered Care Centres: Government, NGO, Private) there were 35,491 looked after children in these facilities (1,965 in Welfare Department Institutions in 2019[38]). There is limited data on healthcare services and access for these children but it is expected that most healthcare needs are generally met.

Recommendations

We require more data on the access to healthcare for children in prison to ensure that it is adequate and appropriate.

[36] Department of Statistics Malaysia (2021). Children Statistics, Malaysia, 2021. https://www.dosm.gov.my/v1/index.php?r=column/cthemeByCat&cat=333&bul_id=d1YxK0tsUWp4RGNHQXZTZTIzNUxWdz09&menu_id=U3VPMldoYUxzVzFaYmNkWXZteGduZz09

[37] Ministry of Women, Family and Community Development and UNICEF Malaysia (2013). The Malaysian juvenile justice system. http://www.iccwtnispcanarc.org/upload/pdf/1672867150Malaysian%20Juvenile%20Justice%20System.pdf

[38] Social Welfare Statistics Report 2019. https://www.jkm.gov.my/jkm/uploads/files/pdf/laporan_statistik/FINAL%20Web%20Upload%20-%20Laporan%20Statistik%202019.pdf

There needs to be an increased understanding of possible harm caused to children placed in institutions (homes, orphanages, correctional residential schools) and work on a strategy for deinstitutionalisation, strengthening families and promoting adoption and foster care.

Protecting the Abused

6-7,000 children are reported as abused yearly. This is a gross underreporting as three local published community prevalence studies on child sexual abuse shows rates between 8-26% of all children (Amar HSS 1996, Kamaruddin 2000, Choo 2011). Data from community studies on maltreatment of 15-17 year olds in 2006 and 10-12 year olds in 2011 showed that at least half have some form of physical or emotional abuse and live in uncertain home environments[39]. Note that approximately 30-40% of all children under 18 years who are identified as sexually abused are often classified as 'rape' and may not be referred to the Welfare Department or paediatricians and only reported to the police.

There are reports of abuse from child care centres, institutions and tahfiz schools (see SUHAKAM[40] annual report). There is no clear idea of the number of unregistered tahfiz schools but media reports suggest hundreds just in the Klang valley alone; often abuse is covered up in religious centres. In addition, the vast majority of childcare centres or nurseries operating are unregistered (in excess of 50,000). In 2016, the Women, Family and Community Development Ministry stated that only 4,240 nurseries and 1,650 childcare centres were registered with the Welfare Department[41]. Unregistered childcare centres or nurseries are of concern as to the potential for poorer children care and lack of supervision.

Schools are not uncommon locations for abuse to occur[42,43], but often the investigation is internal and no report is made to the relevant authorities. Over the years, as a paediatrician, I have experienced a number of occasions where teachers have abused children; physically, sexually and emotionally. The classical response is to transfer teachers to another school. This denies the reality that these teachers may continue to abuse children in the new school and, in addition, the child does not receive appropriate support and care.

Despite the mandatory nature of the Child Act, the empowerment of Social Welfare Officers as 'child protectors' and the vast and comprehensive powers conferred on them, the Welfare

[39] Amar-Singh HSS (2018). Child violence and maltreatment in Malaysia. Berita MMA Vol.48.
[40] Human Rights Commission of Malaysia (SUHAKAM) (2020). Annual report 2019. https://www.parlimen.gov.my/ipms/eps/2020-11-04/ST.88.2020%20-%20ST%2088.2020.pdf
[41] Dr Amar Singh HSS (2018). Unregistered childcare centres a concern. TwentyTwo13. https://twentytwo13.my/expressions/unregistered-childcare-centres-a-concern/
[42] Azrul Mohd Khalib (2021). The uncomfortable reality of abuse in our schools. Malaysiakini. https://www.malaysiakini.com/letters/574879
[43] Amar Singh HSS (2019). When Teachers Abuse Children. CodeBlue. https://codeblue.galencentre.org/2019/10/07/when-teachers-abuse-children-dr-amar-singh-hss/

Department often appears to be powerless[44]. In recent years, I have increasingly noticed that some children reported as possible abuse to the Welfare Department are not brought to paediatricians for examination, denying appropriate health access (in these circumstances, Welfare appears to determine there is no abuse on their own accord).

Recommendations

The Welfare Department must not fail its child protection role, regardless of the situation (religious institution, VIP, etc).

All children suspected to be abused, under the age of 18 years, must be examined by paediatricians trained in child abuse to determine if abuse has occurred.

All child care centres, schools and institutions that care for children (day care or residential) must be registered and have their premises inspected for child safety and have a clear mechanism for the reporting of suspected abuse.

Conclusion[45]

It is important to recognise that the major issue in health access for children is the 'Social Determinants of Health'. Families who are poor, disadvantaged, marginalised and disabled end up having the poorest access to health care; these are the children who have the highest mortality and morbidity. Health services need to be targeted at reaching these populations. Unfortunately, many of our services are urban-based and focused on those that have some wealth.

Within MOH, paediatricians and managers tend to focus on disease and not health (Paediatrics not Child Health). The present model of our healthcare is curative; it is doctor and illness focused, expensive, fragmented and institutional based. The primary care success of antenatal and child health clinics with immunisation, growth and development focus has not been sustained and not duplicated especially in urban settings. Hospitals 'eat' a large proportion of all health resources (60-70%) in terms of funding, manpower and development. In recent decades there has been an 'explosion' of tertiary level specialised services as means to 'meet' the health needs of the community. We no longer run Ministries of Health (MOH) but Ministries of Disease (MOD); an institutionalisation of medicine.

The Private-Public divide has also worsened our child health services. The private sector is largely profit driven with no major incentive to promote preventative health. The commercialisation of healthcare, the use of healthcare as a means of obtaining financial wealth, has undermined the trust of individuals and communities in healthcare professionals.

[44] Amar-Singh HSS, et al (2020). The powerlessness of our Welfare Department. Malay Mail. https://www.malaymail.com/news/what-you-think/2020/01/14/the-powerlessness-of-our-welfare-department-amar-singh-hss/1827842

[45] Amar-Singh HSS. Current Child Health Care Challenges & Suggestions: Improving Child Health Services in Malaysia. September 2019. Malaysia. (Note that this was written for the 12th Malaysia Plan -RMK 12- and submitted to the Ministry of Health Malaysia)

There is inadequate financial resources and health spending by governments, especially on those most in need with limited access to health care. Institutionalised corruption and corrupt practices have a significant impact on the healthcare system in terms of spending and development.

We require a transformative health service which focuses on community care; one that enables and empowers the community to care for themselves[46]. In the end, access to health does not mean going to hospital but healthcare reaching you - community outreach and empowerment are as important as clinics and hospitals.

We need a healthcare system that is developed for children and families[47], and not one that is developed for managers and the healthcare professional. This means listening to and respecting the opinions of the public we serve and planning health services alongside them.

We need to revolutionise the training of our healthcare professionals and move away from a disease approach. We need to provide incentives for our brightest minds to work in the community and in prevention activities. We need to encourage clinicians to spend at least 40% of their working time in the community. We need to dramatically increase funding and manpower resources for public health. We need to develop and enlarge mobile health services to meet urban child health needs.

Child health is critical for the nation's health. If we do not take care of and invest in children we will have 'failed' adults. It is important that the government recognise and respond to the serious health changes posed by rapid socio-economic mal-development. Solutions for change often lie beyond the health sector, and require the engagement of many different sectors of government and society. In this era, individuals and communities have the capacity to take the initiative to advocate for change and work to improve child health and secure a future for their children.

***In all actions concerning children**,*

whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies,

***the best interests of the child shall be a primary consideration**.*

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[46] Amar-Singh HSS (2019). Developing Care in the Community. Roundtable Three: Human Capital for Health in Malaysia. People's Health Forum. Kuala Lumpur, Malaysia. September 2019. Available here: http://bit.ly/39ArFCK

[47] Amar-Singh HSS et al (2021). What True Keluarga Malaysia Means and Looks Like for Our Children. Malaysiakini. https://www.malaysiakini.com/columns/599985

Special Focus on the Impact of Covid-19 on Child Health[48]

Covid-19 is a great distractor that has siphoned off resources, energy and focus on child health. It is anticipated that the impact of Covid-19 will set us back by decades. It is likely that we will continue to see worsening malnutrition, psychological morbidity, demographic change and limited educational outcomes for many generations to come. Childhood immunisation efforts have been interrupted in a number of countries (United Nations 2021). It is expected that gains in child mortality will be halted or slowed down. A summary of the key impacts include:

1. Downward Poverty Spiral

It is anticipated that the loss of income and jobs will push more of the population into poverty. In Malaysia this has been estimated as an additional 5-8% of the population, which translates into an added 2-3 million children thrust into serious poverty.

2. Worsening Childhood Malnutrition

The increasing poverty, decrease in CSO support, decrease in charity and corporate giving, and loss of schooling means that malnutrition in children will worsen with long term consequences for height growth. For example, a sizable proportion of children in Malaysia, with poor food security, who depended on the school-based Supplementary Food Programme, have now lost this resource. In addition, support services and community feeding programmes for indigenous children have been impaired or retarded in growth.

3. Interrupted Education

Schools have been closed intermittently and attempts have been made to move schools to online classes. There is a huge digital divide (unequal access to technology) and disparity between different social groups, worsening the access to education. Data is emerging that children from poorer communities are losing interest in schooling. Children with disabilities have been the hardest hit by a loss of education and therapy.

4. A Generational Scar/Gap

Due to Covid-19 many couples are delaying getting married or postponing having a child. This reduction in planned births will take its full effect in 2021 where we will see a major change in births. The reduction in yearly birth volume may last much longer after Covid-19 due to increased poverty and the need to rebuild lives. In Malaysia the annual reduction in total births of 1.5-2.5% has accelerated to 5.9% in 2020 and 10.8% in 2021. The impact of this 'lost generation' will be seen in the education system (reduction in students/classes), long term manpower needs and health considerations (increased later age pregnancies).

Special Note on the Climate Emergency

There is a need to address the growing climate emergency; it is the major health challenge of our time and children will be the most affected. It was estimated in 2012 that 26% of childhood deaths and 25% of the total disease burden in children under 5 could be prevented through the reduction of environmental risks such as air pollution, unsafe water, sanitation, etc (much urban poor relate)[49]. Climate change and the impending climate emergency threatens to engulf us, will reverse all child health (SDG 3) gains.

[48] Amar-Singh HSS (Nov 2020; updated August 2021). Covid-19 and its Impact to Future Generations. Speaking for the Unspoken 2020: The Vulnerable Population and Covid-19. Medico-Legal Society of Malaysia. https://bit.ly/3hMc7Qq

[49] Prüss-Ustün A, et al (2016). Preventing disease through healthy environments: A global assessment of the environmental burden of disease from environmental risks. World Health Organization.