National Key Result Areas for Special Needs Children (Health)

Safurah Jaafar

Format/Scope

1. Basics of disease prevention
2. Preventing congenital anomalies
   - why, what, how
   - current programmes
3. Role of PHC
   - why, what, how
   - challenges
4. Future strategies

National Screening Services

Pre - Marital
- Rubella
- HIV
- Thalassemia
- Hepatitis B

During Pregnancy
- HIV
- STI
- Rhesus

Neonatal Period
- Congenital Hypothyroidism
- G6PD

Post – neonatal and beyond
- Immunisation Programme
- Accident Prevention (1999)

Syphilis Screening - 1983

- All pregnant mothers tested for VDRL and TPHA levels
- Treatment for those positive

Screening of Syphilis Among Antenatal Mothers Malaysia, 2002 - 2011

<table>
<thead>
<tr>
<th>YEAR</th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>264,682</td>
<td>268,632</td>
<td>267,036</td>
<td>264,911</td>
<td>264,458</td>
<td>261,682</td>
<td>260,913</td>
<td>266,942</td>
<td>265,036</td>
<td>264,458</td>
</tr>
<tr>
<td>Women in attendance at the public testing clinic</td>
<td>265,700</td>
<td>269,344</td>
<td>269,400</td>
<td>266,856</td>
<td>266,400</td>
<td>263,856</td>
<td>263,344</td>
<td>269,344</td>
<td>268,400</td>
<td>267,856</td>
</tr>
<tr>
<td>Number screened for syphilis</td>
<td>259,700</td>
<td>263,344</td>
<td>263,400</td>
<td>260,856</td>
<td>260,400</td>
<td>257,856</td>
<td>257,344</td>
<td>263,344</td>
<td>262,400</td>
<td>261,856</td>
</tr>
<tr>
<td>Percentage screened for syphilis</td>
<td>98.20%</td>
<td>98.57%</td>
<td>98.63%</td>
<td>98.32%</td>
<td>98.07%</td>
<td>98.07%</td>
<td>98.07%</td>
<td>98.07%</td>
<td>98.07%</td>
<td>98.07%</td>
</tr>
</tbody>
</table>

Source: AIDS/STI Section, Ministry of Health Malaysia
Rubella Screening and Immunisation - 1987

- Started with Screening – 1985
- Immunisation and Seroconversion
- Immunisation for all
  - Starts with all female students 6 -12 years old - 1996
  - Given to all 12 year old
  - MMR given to 12 mths old.
- Reduction of Cong Rubella Syndrome (through study)

Declining rate of birth of infants homozygous for β-thalassemia in Sardinia since 1975

Thalassemia Screening - 2008

<table>
<thead>
<tr>
<th>Year</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>141,708</td>
<td>208,316</td>
<td>202,036</td>
<td>307,968</td>
</tr>
<tr>
<td>Number of blood samples sent for 2nd level screening / confirmatory test</td>
<td>55,308</td>
<td>59,686</td>
<td>68,047</td>
<td>62,518</td>
</tr>
<tr>
<td>Confirmed trait</td>
<td>1,719</td>
<td>1.2%</td>
<td>3,240</td>
<td>1.55%</td>
</tr>
</tbody>
</table>

Source: Family Health Development Division, Ministry of Health
Birth of new thalassaemia

Surrogate indicator for an effective prevention programme

Birth of new Thalassaemia patients

(By States, 2006 – 2009)

<table>
<thead>
<tr>
<th>State</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>PULAU PINANG</td>
<td>34</td>
</tr>
<tr>
<td>SABAH</td>
<td>208</td>
</tr>
<tr>
<td>KEDAH</td>
<td>66</td>
</tr>
<tr>
<td>KELANTAN</td>
<td>30</td>
</tr>
<tr>
<td>JOHOR</td>
<td>41</td>
</tr>
<tr>
<td>MELAKA</td>
<td>19</td>
</tr>
<tr>
<td>NEGERI SEMBILAN</td>
<td>10</td>
</tr>
<tr>
<td>PERAK</td>
<td>21</td>
</tr>
<tr>
<td>PERLIS</td>
<td>8</td>
</tr>
<tr>
<td>PULAU PRATAN</td>
<td>35</td>
</tr>
<tr>
<td>SELANGOR</td>
<td>17</td>
</tr>
<tr>
<td>TERAENINGAN</td>
<td>23</td>
</tr>
<tr>
<td>W. PERSEKUTUAN(KL)</td>
<td>39</td>
</tr>
<tr>
<td>W. PERSEKUTUAN(M)</td>
<td>27</td>
</tr>
</tbody>
</table>

Birth of new Thalassaemia patients

(Malaysian Thalassaemia Registry 2010 – unpublished data)

PREVENTION PROGRAMME CRUCIAL TO REDUCE NUMBER OF NEW BIRTHS

- Patients may present as early as 4 months (Thalassaemia Major) or as late as 4-5 years of age (Thalassaemia intermedia)
- Real-time data will change as they reflect immediately the data as they are being entered
- May not reflect those that present at a much later age
- *Under reporting in 2010 (No Research Assistants to enter data)

HIV ANTENATAL SCREENING

Starting from 2002 - All pregnant Mothers are screened for HIV

<table>
<thead>
<tr>
<th>YEAR</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>New</td>
<td>388,388</td>
<td>381,686</td>
<td>396,951</td>
<td>410,980</td>
<td>415,427</td>
<td>443,453</td>
</tr>
<tr>
<td>Total</td>
<td>349,922</td>
<td>377,153</td>
<td>380,346</td>
<td>394,673</td>
<td>403,287</td>
<td>413,862</td>
</tr>
<tr>
<td>Positivity</td>
<td>95.78%</td>
<td>99.85%</td>
<td>99.65%</td>
<td>99.43%</td>
<td>98.13%</td>
<td>99.62%</td>
</tr>
<tr>
<td>Confirmed (HIV+)</td>
<td>110</td>
<td>170</td>
<td>190</td>
<td>200</td>
<td>171</td>
<td>239</td>
</tr>
</tbody>
</table>

PREMARITAL HIV SCREENING

- Premarital HIV Started with one state on 2002
- Roll-out to half the country in 2007
- Roll-out to all states in 2009

All MUSLIM couples before getting married are required to a 2-5 days Premarital course. HIV testing certificate required before Nikah.
Early Detection

Child Developmental Assessment
- Fine Motor – head control
- Hearing
- Psychological and speech development

Number of births in Sabah contributes ~11% of total births.

Total Number of children aged 0 - 18 years detected according to types of disabilities for the year 2011 (Malaysia)

Premarital HIV Screening

Preventable Diseases

Incidence of neonatal tetanus (per 1,000 LB): 1975 – 2011

Incidence rate of immunisable diseases:

Number of children aged 0 - 18 years detected with disabilities according to age for the year 2011 (Malaysia)

Preventable diseases include:
- Measles
- Polio
- Diptheria
- Tetanus
- Hepatitis B
Number of diphtheria cases, 1975 – 2011

Number of Pertussis cases; 1975 – 2011

Immunisation Coverage 2007 - 2011

Immunisation Coverage 2004 - 2011

ROLE OF THE MOH

Disability limitation and Rehabilitation

Child:

a. Medical Intervention:
   e.g.: Surgery, medication, assistive devices
b. Therapy:
   Physiotherapy, Occupational Therapy, Speech

c. Individual Care Plan:
   Care plans based on capabilities of individual child with focus on improving function and towards independence
Disability Limitation and Rehabilitation

- **Parents**
  - Parent Education to improve knowledge and skill to help child
  - Counseling - individual and group counseling

- **Family**
  - Family Education including siblings to enable understanding and skill development to assist child with special needs
  - Family support groups

- **Community**
  - Interagency networking to improve results - making environment more friendly. Providing assistance to Community Based Rehabilitation Centers

MEDICAL – SOCIAL INTERFACE

- bridge the medical rehabilitative services provided in the hospitals and CBR services by the Social Welfare Department or those run by the NGOs.
- enable early detection and intervention as well as continuity of care for these special group of children in the primary health care level.

REHAB – Multidisciplinary Team

- PT
- OT
- SLT
- MA
- NURSES - trained to manage
- Health Workers
- CBR Workers
- Social Welfare Officers
- Teachers
- Specialist
- Medical Officer
- **PARENTS / CARERS**

Case discussion – decide as a group child's diagnosis, plan intervention and apply

PWD ACT 2008

Seksyen Perkara

33 Habilitasi/rehabilitasi
34 Perkhidmatan di rumah, kediaman & sokongan komuniti
35 Akses kepada kesihatan
36 Pencegahan dan pengesanan awal kecacatan
Penggalakan kajian
37 Pengadaan personel kesihatan
38 & 39 Perindungan orang dengan ketidakupayaan teruk
40 Keadaan berisiko dan kecemasan

WHO: INTERNATIONAL CLASSIFICATION OF FUNCTIONING AND DISABILITY
ROLE OF MOH: Prevent / Reduce Participation Restriction

Disability Limitation and Rehabilitation
Assistive Device
Reduce Barriers
Adaptations etc.

Rehabilitation services available in:
- all hospitals
- CBR (outreach services to CBR)
- 57 OT's and 56 PT's in health clinics

Interagency Collaboration - Achievements

1. Policy Development and Implementation
   - Development of format for registration of child with special needs and suggested placement in school/CBR etc.
   - Development of National Health Program for Prevention and Management of Specific Disabilities
   - Development of screening instruments for children in school for early identification of learning problems

2. Development of Health Education Material
   - NGO involvement - depth of knowledge in specific disabilities
     • Spastic center
     • Dyslexia Society
     • Autistic Society
     • Malaysian Care
     • Associations of the Deaf and for the Deaf
     • Malaysian Association for the Blind
     • Malaysian Mental Health Association
     • Etc.

3. Training module development
   - Development of manual and training of Caregivers in Institution and at home

Resources for Prevention of Blindness
Resources for Prevention of Deafness

Resources for of children with special needs
4. Training Awareness

Training on prevention and early detection

- Parents and Carers –
  - Buku Rekod Kesihatan Kanak-Kanak 0-6 tahun
  - Modul Intervensi awal – network with BAKTI
- Care providers in nursery and kindergarten –
  - network with UPM for training of PERMATA program
- Panel Penasihat
  - On early detection and registration of PWD with Social Welfare

Training of Caregivers in Institution and at home

- Network with Cheshire Home, DSW and MAKPEM

National Level Committees for health care for PWDs

- Technical Committee on Health Care (since 1996)
- Quality of Life Committee (since 2009)

both committees include NGOs and other agencies

Program Utama and Pencapaian JK Quality Life Care Bagi Tahun 2010-2011

1. Pengesanan awal kecacatan – improve quality and KPI
2. Penggalakan kajian – Development of Clearinghouse for Disability
3. Pengesahan OKU bagi urusan pendaftaran – Training
4. Kesihatan seksual dan reproduktif OKU – TOT
5. Perkhidmatan dirumah / institusi dan sokongan komuniti – provision of support services by NGO
6. Keperluan personel kesihatan bagi melaksanakan rehabilitasi – paper on needs of country presented to Majlis

Future

- MOH has revised the 1996 Health Care POA for PWD to include elements in the PWD ACT and the Convention on the Rights of PWD
- POA has been approved and includes plans for 2011 - 2020
Strategies

- Empower individual, families and communities through provision of adequate knowledge and skills
- Strengthen the provision of promotive, preventive and rehabilitative services, ensuring accessibility to all
- Establish outreach programmes/activities using setting approach
- Resource allocation and manpower development
- Foster intersectoral collaboration with stakeholders through networking and smart partnerships
- Strengthen monitoring and evaluating mechanism and conduct research

Acknowledgements