

Plans for Improving Services for Children with Special Needs

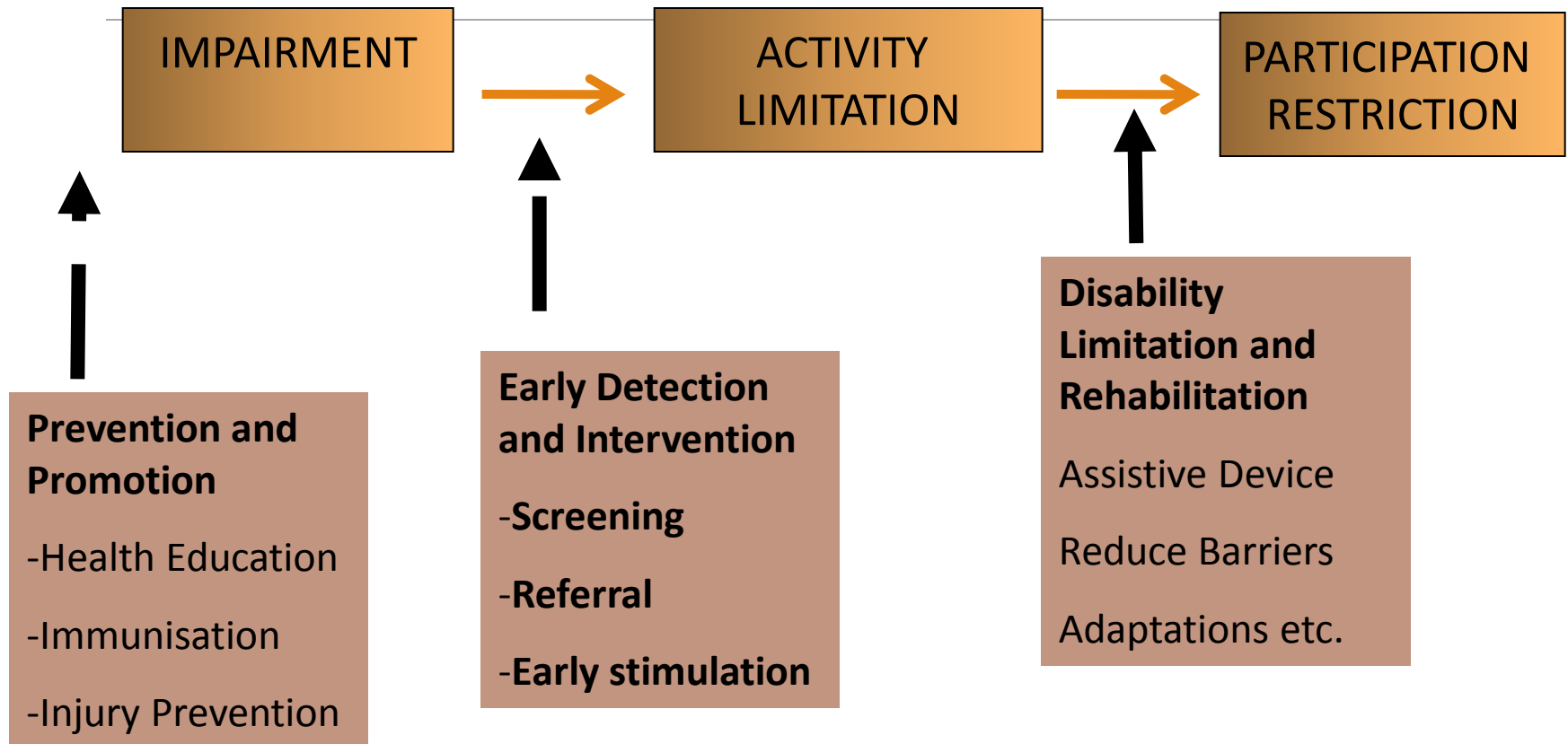
SAFURAH JAAFAR



Statement of Principles for Children with Special Considerations

1. Equitable access for prevention, treatment and rehabilitation services
2. Respect for the diversities of communities
3. Community-based partnerships
4. Representation of the diversity of communities, in all phases of emergency management;
5. Accountability for implementation at local, regional and state levels.

ROLE OF THE MOH



Early prevention and intervention

Lifecycle of a problem

Prevention

Initiatives aimed at preventing the emergence of a problem (usually population-based)

Early intervention

Initiatives targeted at an emerging problem, to prevent it from escalating or to reduce its severity

Response

High level of intervention required to remediate or rehabilitate an established problem

Desired shift in resource focus

Desired shift in service delivery focus

Primary prevention

- Includes efforts to control the underlying cause or condition that results in disability, e.g. *immunisation; Tetanus toxoid/ Calcium during pregnancy*

Secondary prevention

- aims at preventing an existing illness or injury from progressing to long-term disability, e.g. *newborn hearing screening*

Tertiary prevention

- refers to specialised measures to mitigate the effects and improve outcomes once a disability is established, e.g. appropriate rehabilitation services

Early intervention for child development

Early Childhood Intervention

‘Coming between’ any negative effects that exposure to particular risk factor/s (e.g. poverty, low birth weight, family stress etc.), a developmental delay or disability might have on a child’s development

ECI consists of...

- **multidisciplinary services** provided to children from birth to five years of age
- to **promote child health and well-being,**
- **enhance emerging competencies,**
- **minimise developmental delays,**
- **remediate existing or emerging disabilities,**
- **prevent functional deterioration,**
- **and promote adaptive parenting and overall family functioning.**

Handbook of Early Childhood Intervention – Shonkoff and Meisels (2000)

children judged at risk for poor developmental outcomes versus children with identified developmental disabilities or delays.

The programs targeted for **at-risk populations** often are conceptualized as **preventive interventions**, whereas those serving children with **known problems** are considered **treatment programs**.

(S. L. Ramey & Ramey 1992)

Early detection

Child Developmental Assessment



• Gross motor – head control

• Fine Motor – reaching for toy



• Hearing

• Psychological and speech development



Unit Pendidikan Kesihatan
Negeri Perak

Jabatan Kesihatan

Steps for identification

- The child is evaluated.
- A group considers the results and determines eligibility.
- Individual educational plan is written for the child.
- Services are provided.
- Progress measured and reported.
- The child is re-evaluated at least every 3-6 months.

Domain assessed:

Physical Development

Language

Social
Functioning/Social-
Emotional Development

Cognition

Temperament

Attachment

Brain Function

Mental Problems

National Screening Services

Pre - Marital

HIV

Thalassaemia

Hepatitis B

Neonatal Period

Congenital
Hypothyroidism

G6PD

During Pregnancy

- HIV
- STI
- Rhesus

National Screening Services

Post –neonatal and beyond

Immunisation Programme

polio (1972) , measles (1984) rubella (1988) dan Hib (2002)

Accident Prevention (1999)

National Iodine Deficiency Disorder Prevention and Control Programme
(1995)

Prevention and Control Programmes for Blindness (1996) and Deafness
(2003)

Violence and Injury Prevention Programme (2007)

National Screening Services

Syphilis Screening - 1983

All pregnant mothers tested for VDRL and TPHA levels

Treatment for those positive



National Screening Services

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)

National Screening Services

Thalassaemia Screening - 2008

Rawatan Pesakit Talasemia

(Talasemia major)

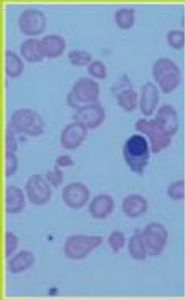
- Pesakit memerlukan transfusi darah secara berterusan setiap bulan sepanjang hayat.
- Transfusi darah berterusan akan menyebabkan pengumpulan zat besi di dalam organ utama badan seperti hati, limpa, jantung dan kelenjar endokrin yang akhirnya merosakkan fungsi organ-organ tersebut.
- 5 kali seminggu diperlukan untuk rawatan penyingkiran zat besi yang berlebihan.
- Pemindahan sum-sum tulang sekiranya ada penderma yang sesuai di kalangan keluarga.

Talasemia Major Boleh Dicegah!

- Jalani ujian talasemia sekiranya anda:
 1. Seorang remaja
 2. Mempunyai sejarah keluarga talasemia
 3. Ingin mendirikan rumahtangga
- Elakkan perkahwinan sesama pembawa gen talasemia.



Sel darah merah normal



Sel darah merah talasemia

Masa depan anak anda di tangan anda.
Jalanilah Ujian Talasemia.



Untuk maklumat lanjut:
Sila hubungi
hospital dan klinik berdekatan atau
Persatuan Talasemia

TALASEMIA
Apa setiap Warga Malaysia perlu tahu!



KEMENTERIAN KESIHATAN MALAYSIA



National Screening Services

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

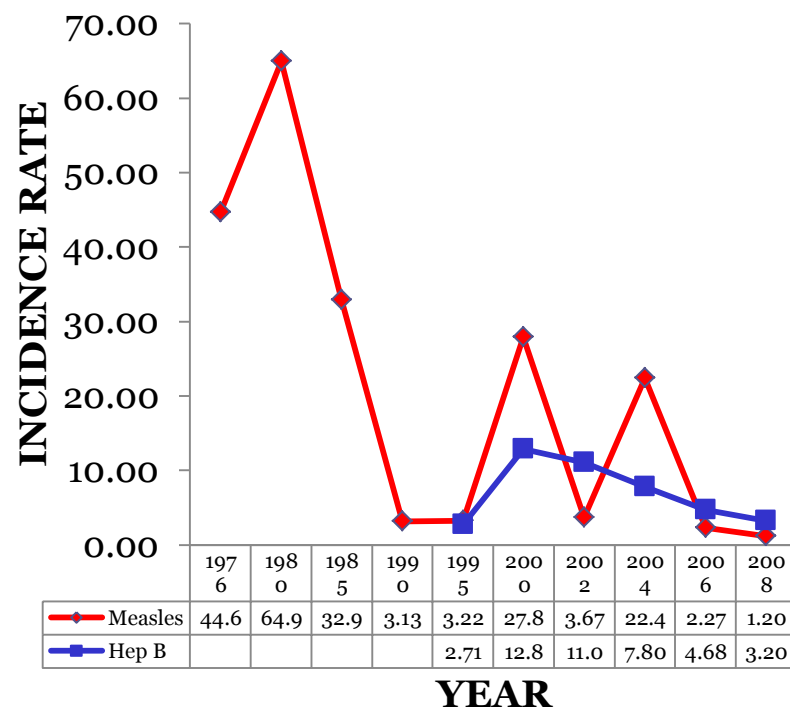
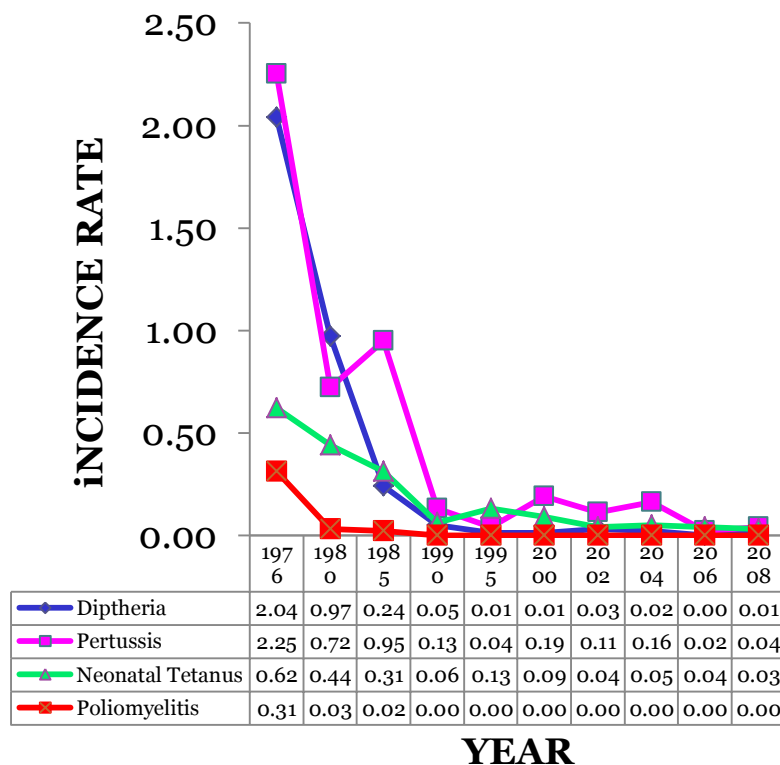
All MUSLIM couples before getting married are required to a 2-days Premarital course. HIV testing certificate required before Nikah.



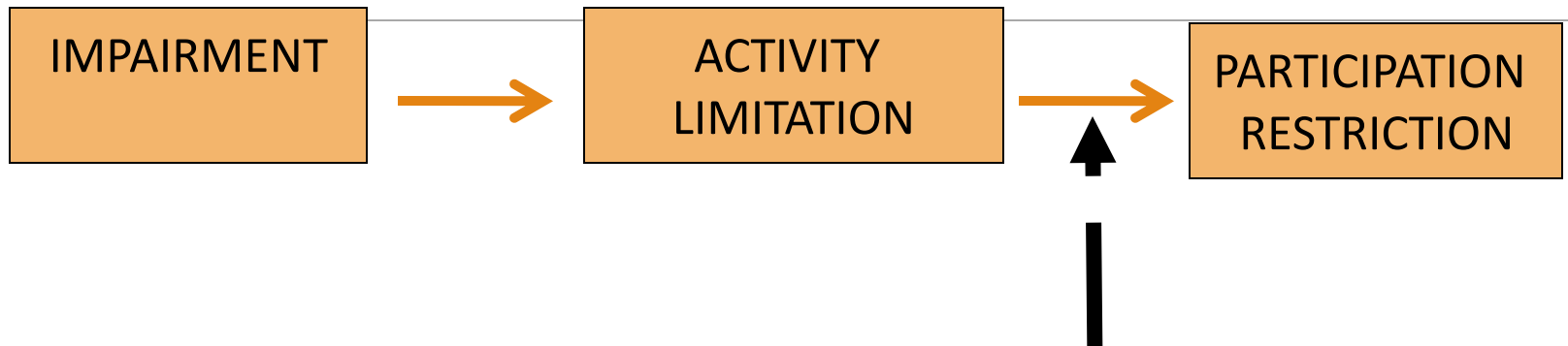
INCIDENCE RATE IMMUNISABLE DISEASES :

DIPHTHERIA, PERTUSSIS, NEONATAL TETANUS AND
POLIOMYELITIS , 1976 -2008

MEASLES AND HEPATITIS B, 1976 -2008



ROLE OF MOH : Prevent / Reduce Participation Restriction



Rehabilitation services available in

- all hospitals
- 240 health clinics
- CBR (outreach services to CBR)
- 57 OT's and 55 PT's in health clinics

Disability Limitation and Rehabilitation

Assistive Device

Reduce Barriers

Adaptations etc.

Disability limitation and Rehabilitation

REHAB – Multidisciplinary Team

- PT
- OT
- SLT
- MA
- NURSES- trained to manage cwsn
- 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

Disability limitation and Rehabilitation

1. 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

Children are Packaged with Families Caregivers and Community



Disability limitation and Rehabilitation

2. Parents

- a. Parent Education to improve knowledge and skill to help child
- b. Counseling – individual and group counseling

3. Family

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

4. Community

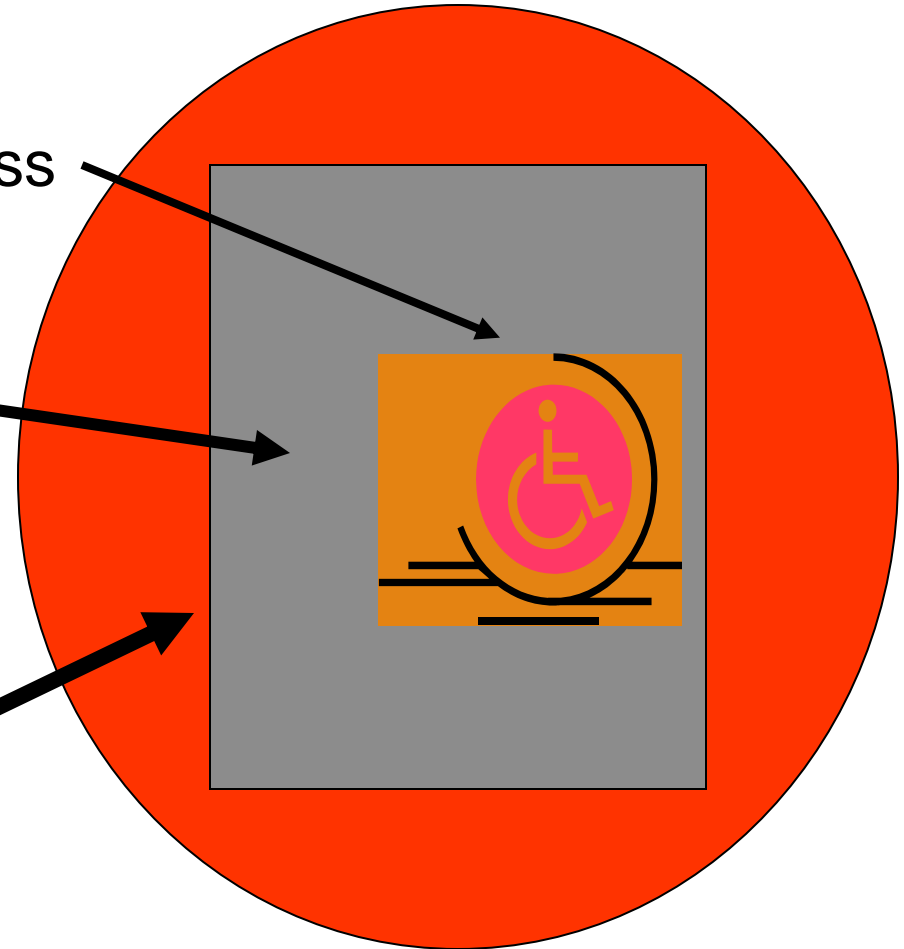
- a. Interagency networking to improve results – making environment more friendly . Providing assistance to Community Based Rehabilitation Centers

Counseling With Parents of Exceptional Children

- Parents suffer range of emotions at not getting the child they wanted
- Parents may over protect or under protect
- Parents may sacrifice their lives to their child

Together to help PWD attain Quality Life

- PWD – Build on strength,
work on weakness
- Family
 - Acceptance
 - Motivation
 - Support
- Community
 - Enabling environment
 - Opportunities



Interagency Collaborations

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

Interagency Collaborations

Understanding Socio-Cultural Difference

Cultural differences:

- Race
- Ethnicity
- Religion
- Color
- Language
- Location
- Group

Values

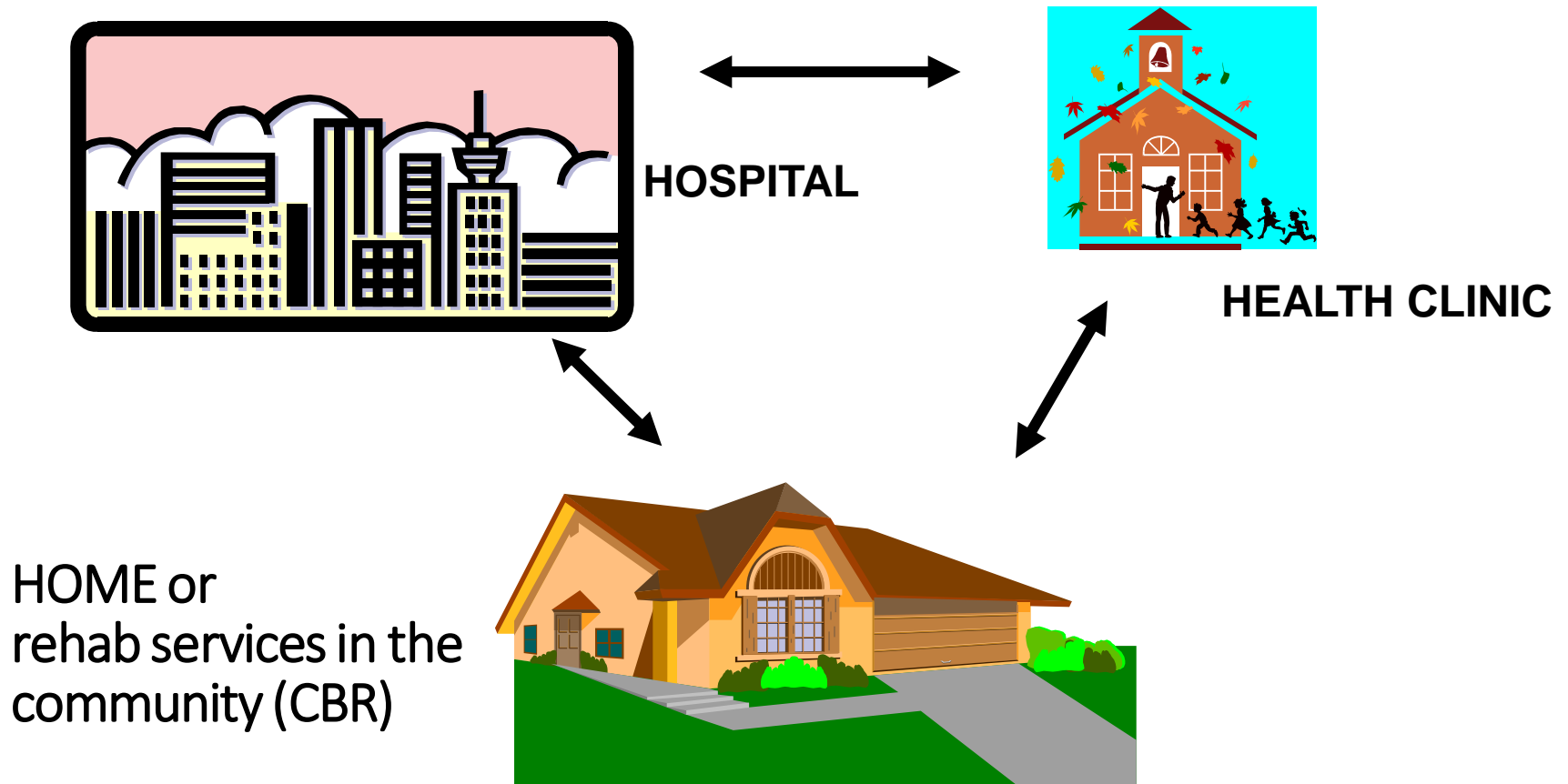
Attitudes

Prejudices

Diversity: race, ethnicity, gender, social class and lifestyle

Interagency Collaborations

Connecting the loop



Interagency Collaborations

Working with Disability Organizations

- In-home
- At-school
- Provide specific Information for first responders

Involve persons with disabilities and their families in planning

programs where persons with special needs congregate:

Interagency Collaborations

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.**



Getting it right: Have we helped ?

- The child can play and adapt to his/her surrounding
- The child develop good relations with siblings, friends and classmates
- The child learn to solve his own problems
- The child to feel better about himself
- Parents and teachers interact in ways that help the child
- The child with his self concept
- The child understand, through my behavior, that he is a valuable human being

Training

Training and Dissemination

Train community professionals in assessment and evidence-based treatment methods

Educate policy makers and parents

Create web-based tools and parent help-line

Public and Private Conference and awareness programs



Training

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

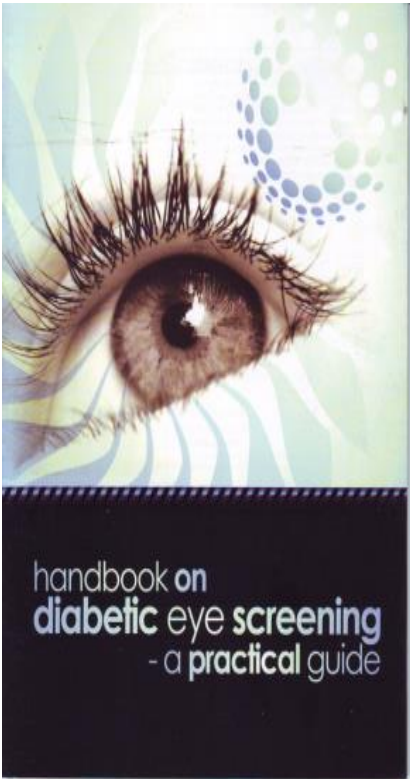
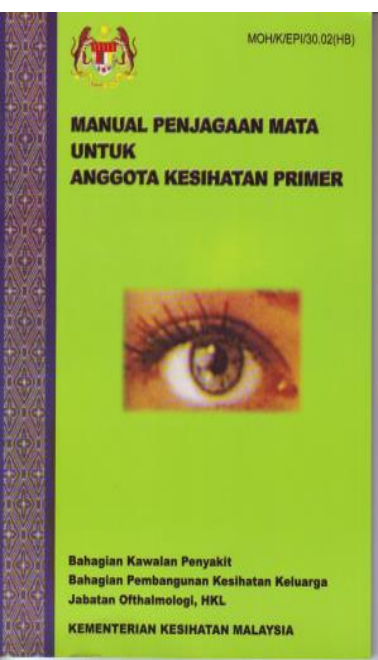
- On early detection and registration of PWD with Social Welfare

- ## **Training on management of child with delay in 'gross motor, fine motor, ADL, visual impairment, communication, personal & social**
- Network in the training of health personnel, teachers and CBR workers

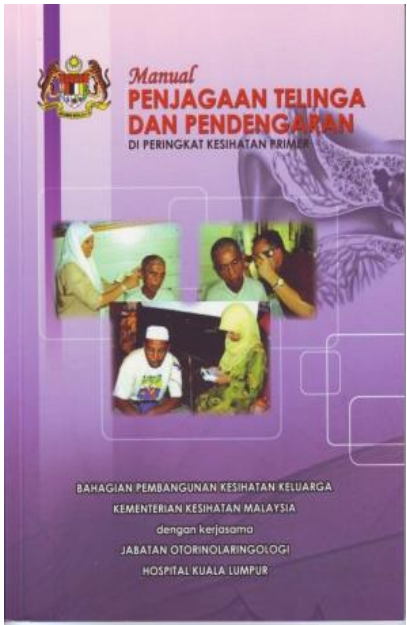
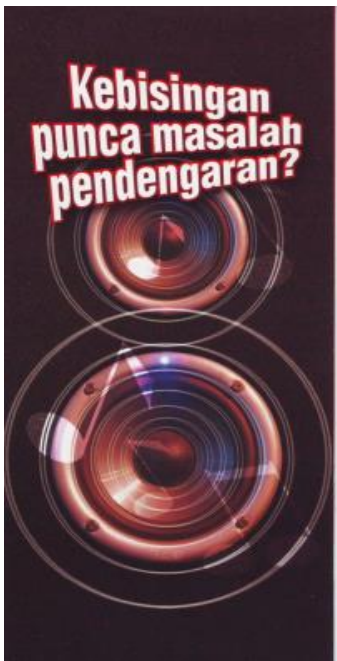
Training of Caregivers in Institution and at home

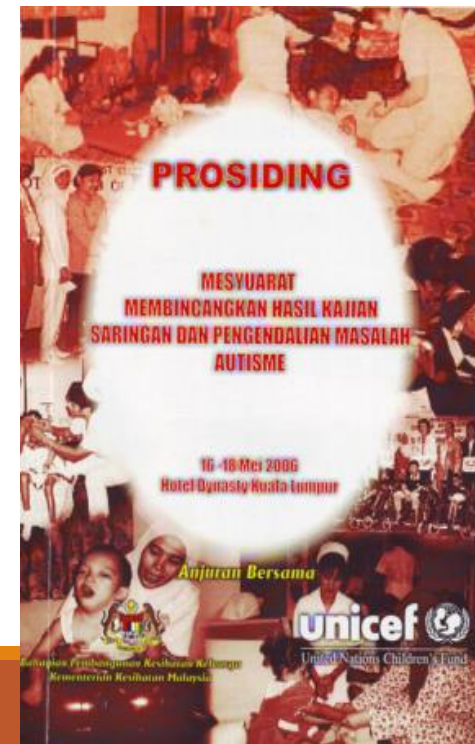
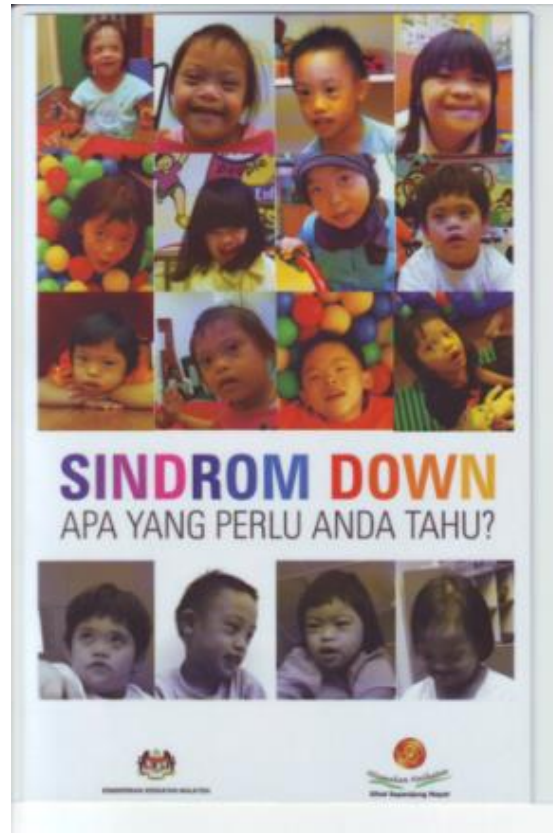
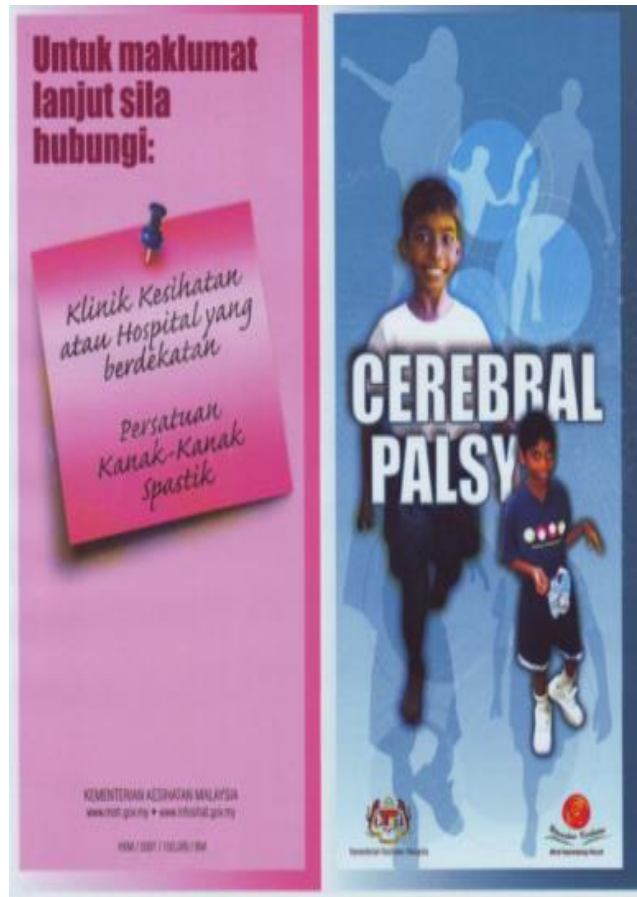
- Network with Cheshire Home , DSW and MAKPEM

Resources for Prevention of Blindness



Resources for Prevention of Deafness





Resources for of children
with special needs

Training module development



Caregiver Training Manual

Basic Care of People with Disabilities
in Institution & at Home

by Family Health Development Division, Public Health Department,
Ministry of Health, Malaysia



In Collaboration with



Malaysia Social Welfare Department,
Ministry of Women, Family and Community Development

Selangor Cheshire Home

National Council of
Cheshire Home Malaysia



Modiul Latihan Bagi Penjaga

Jagaan Asas Orang Kurang Upaya
Di Institusi & Di Rumah

oleh Bahagian Pembangunan Kesihatan Keluarga,
Jabatan Kesihatan Awam, Kementerian Kesihatan Malaysia



Dengan Kerjasama

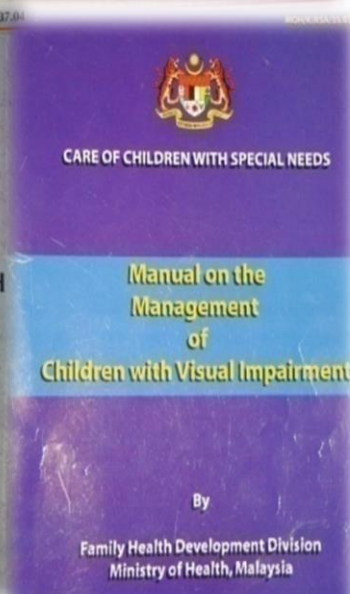
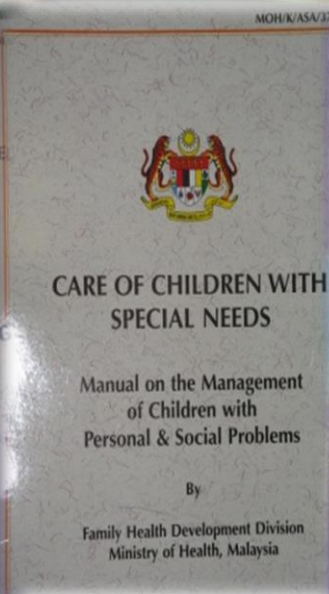
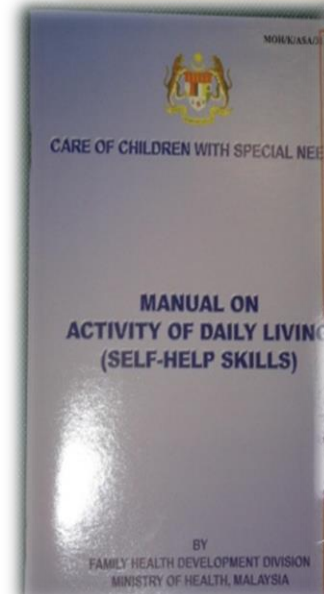
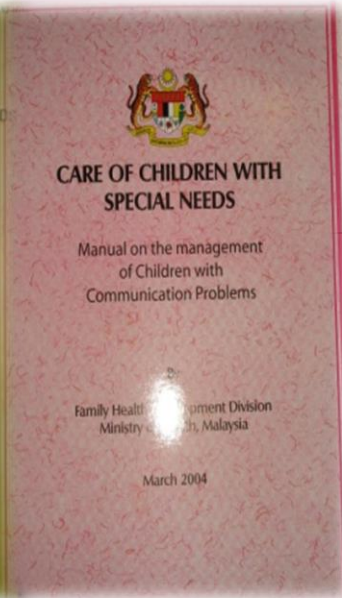


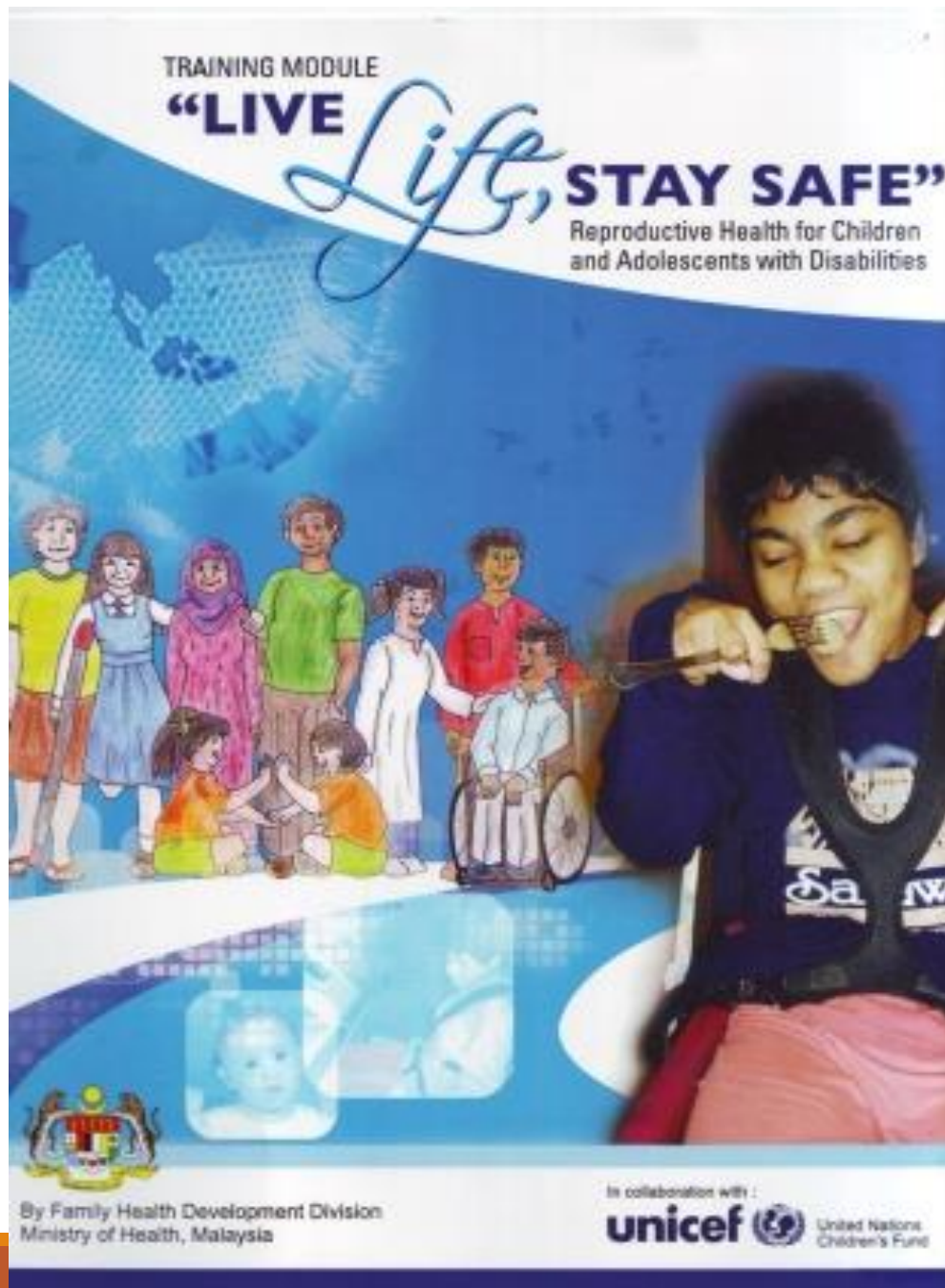
Jabatan Kebajikan Masyarakat, Malaysia,
Kementerian Pembangunan Wanita, Keluarga & Masyarakat

Rumah Amal Cheshire,
Selangor

Majlis Kebangsaan Rumah
Amal Cheshire, Malaysia

Development of
manual and
training of
Caregivers in
Institution and at
home





Module was launched
in 2009

Training began in
2010

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

Ahli JK *Quality Life Care*

Chairman : Director General of Health

- 1) (Majlis Pemulihan Malaysia)
- 2) (Persatuan Kesihatan Mental Malaysia)
- 3) (Universiti Kebangsaan Malaysia)
- 4) (Persatuan Doktor Perubatan Malaysia)
- 5) (Persatuan Orang Buta Malaysia)
- 6) (Rumah Bethany)
- 7) (Persatuan Wanita OKU)

JK *QUALITY LIFE CARE* chaired by DG of Health

SECTION 33 – 40 OF THE ACT

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

Program Utama and Pencapaian *JK Quality Life Care* Bagi Tahun 2010-2015

1. Pengesanan awal kecacatan – improve quality and KPI
2. **Penggalakkan 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 melaksana rehabilitasi – paper on needs of country presented to Majlis

The Commitment ...1

Malaysian government has identified Quality Healthcare & Active Healthy Lifestyle the main Key Result Area (KRA)

KRAs that have been extended to include children with special needs amongst others include:

1. All children are screened early and continuously for special health care needs.
2. Registration and support
3. Community-based service systems are organized so families can use them easily.
4. All youth with special health care needs receive the services necessary to transition to adult life, including adult health care, work, and independence with sound reproductive and sexual health services
5. Establish a clearing house with accumulation of researches in specific area of special needs
6. Comprehensive human resource planning and establishment in addressing the gaps in managing children with special needs

The Commitment ...2

7. increase awareness of the public to participate in disability prevention activities;
8. promote and protect the rights and dignity encouraging training and protecting employment;
9. reduce risk factors contributing to disabilities during pregnancy and childhood
10. promote early intervention and identification of disability, especially during pregnancy
11. implement, family counselling programmes including premarital confidential testing for diseases such as anaemia and thalassemia along with prevention counselling for intra-family marriages;

The Commitment ...3

- 12. promote and strengthen community-based rehabilitation programmes linked to primary care
- 13. facilitate access to appropriate assistive technology and to promote its development
- 14. ensure gender equality in all measures, with special attention to women and girls with disabilities, often subject to social, cultural and economic disadvantages
- 15. ensure provision of adequate and effective medical care to people with special needs
- 16. research and implement the most effective measures to prevent disabilities in

Thank you
