

National Key Result Areas for Special Needs Children (Health)

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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

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National Screening Services

Pre - Marital	During Pregnancy	Neonatal Period
<ul style="list-style-type: none"> Rubella HIV Thalassemia Hepatitis B 	<ul style="list-style-type: none"> HIV STI Rhesus 	<ul style="list-style-type: none"> Congenital Hypothyroidism G6PD

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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)

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Syphilis Screening - 1983

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

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SCREENING OF SYPHILIS AMONG ANTEPARTUM MOTHERS MALAYSIA, 2002 - 2011

YEAR	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
Total New antenatal attendance at the public health facilities	445,283	382,345	381,921	379,461	388,388	381,686	396,951	410,980	415,427	443,453
Number screened for syphilis	280,303	285,723	298,248	292,624	311,5051	365,859	372,949	389,825	410,065	435,619
Percentage screened for syphilis	62.95%	74.73%	79.09%	77.12%	80.20%	95.9%	94.0%	94.85%	98.71%	98.23%
Confirmed syphilis (TPHA+)	23.0.08%	27.0.09%	26.0.09%	29.0.05%	27.0.03%	30.0.09%	28.0.08%	29.0.07%	29.0.04%	30.0.07%

Source: AIDS/STI Section, Ministry of Health Malaysia
Family Health Development Division, Ministry of Health

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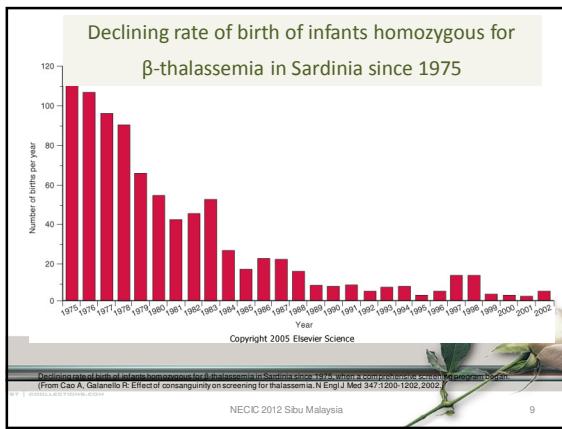
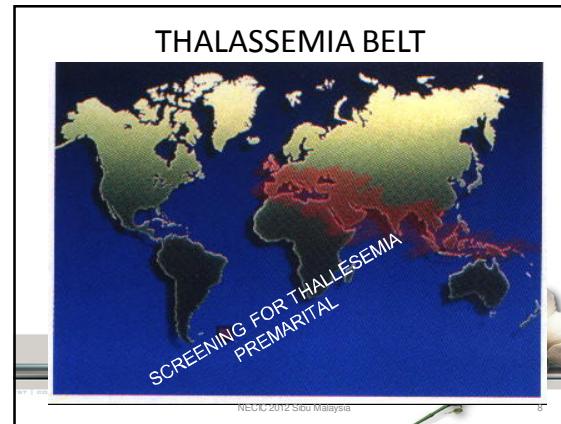
Rubella Screening and Immunisation - 1987

- 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)




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Thalassemia Screening - 2008

VOLUNTARY SCREENING FROM JUN - DECEMBER 2008 = 85,200
2009 = 150,000



TALASEMIA Apa setiap Warga Malaysia perlu tahu!

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THALASSAEMIA SCREENING MALAYSIA, 2008 - 2011

	YEAR	2008	2009	2010	2011				
Total	Number of adolescent and young adult screened in the public health facilities	141,758	209,316	262,236	337,392				
	Number of blood samples sent for 2 nd level screening / confirmatory test (Hb: Normal and MCH≤ 27pg)	25,328	39,966	49,147	62,518				
	Confirmed trait	1,719	1.2%	3,240	1.55%	4,817	1.8%	4,859	1.4%

Source: Family Health Development Division, Ministry of Health

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3.1. Comprehensive Patient Care

State	2006		2007		2008		2009		2010	
	No.	%								
JOHOR	366	7.89	380	7.91	390	7.89	394	7.84	381	7.64
KEDAH	411	8.99	426	9.05	450	9.1	481	9.31	436	9.15
PERAK	269	5.23	303	6.3	307	6.21	311	6.19	304	6.19
MELAKA	119	2.36	124	2.58	128	2.59	130	2.65	133	2.66
NEGERI SEMBILAN	123	2.55	123	2.56	128	2.59	129	2.57	129	2.58
PAHANG	214	4.61	221	4.6	222	4.49	222	4.42	218	4.37
PERLIS	309	6.66	315	6.55	320	6.47	320	6.37	320	6.41
TERENGGANU	94	2.03	96	2	99	2	100	1.99	98	1.92
PULAU PINANG	29	0.44	306	6.37	315	6.37	320	6.37	318	6.37
SABAH	1103	24.85	1212	25.21	1269	25.67	1298	25.83	1306	26.18
SARAWAK	125	2.69	129	2.68	135	2.73	138	2.75	139	2.77
SELANGOR	467	10.06	475	9.88	478	9.87	481	9.57	475	9.52
TERENGANU	151	3.25	155	3.22	159	3.22	159	3.16	158	3.17
KUALA LUMPUR	497	10.71	514	10.69	525	10.62	533	10.51	532	10.66
LABUAN	12	0.26	12	0.25	12	0.24	13	0.25	13	0.26
PUTRAJAYA	5	0.11	6	0.12	7	0.14	7	0.14	7	0.14
TOTAL	4640		4807		4944		5025		4990	

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Birth of new thalassaemia

Surrogate indicator for an effective prevention programme

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Birth of new Thalassaemia patients
Malaysia, 2002 – 2009

PREVENTION PROGRAMME CRUCIAL TO REDUCE NUMBER OF NEW BIRTHS

Year	2002	2003	2004	2005	2006	2007	2008	2009*	2010*
New Births	226	177	192	184	175	167	163	109	?54

• 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)
 (Malaysian Thalassaemia Registry 2010 – unpublished data) Malaysia 14

Birth of new Thalassaemia patients
(By States, 2006 – 2009)

State	TOTAL
JOHOR	41
KEDAH	66
KELANTAN	30
MELAKA	19
NEGERI SEMBILAN	7
PAHANG	10
PERAK	21
PERLIS	8
PULAU PINANG	34
SABAH	208
SARAWAK	17
SELANGOR	32
TERENGGANU	11
W. PERSEKUTUAN(KL)	39
W. PERSEKUTUAN(LABUAN)	2
W. PERSEKUTUAN(PUTRAJAYA)	1
Total	548

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(Malaysian Thalassaemia Registry 2010 – unpublished data)

HIV ANTENATAL SCREENING

Starting from 2002 - All pregnant Mothers are screened for HIV

2006	2007	2008
388,388	381,686	396,951
311,505	365,851	372,749
80.20%	95.9%	94.0%

Starting from 2002 - All pregnant Mothers are screened for HIV
 In 2002, 123 new HIV cases were detected (0.17% from 74,210 respondents).
 In 2004, 24 cases (64.9%) advanced to marriage (n = 37) after antenatal screening and six of them married among themselves.
 Positivity rate from this programme was higher than antenatal screening (0.05%).
 Despite the implementation of antenatal HIV screening programme, marriage application in Johor rose 2.8% in 2004 compared with 2002.
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HIV ANTENATAL SCREENING

YEAR	2005	2006	2007	2008	2009	2010	2011
Total New antenatal attendances in the public health facilities	365,952	377,735	381,686	396,951	410,980	415,427	443,453
Number screened for HIV	349,922	377,153	380,346	394,673	403,287	413,862	443,453
Percentage screened for HIV	95.78%	99.85%	99.65%	99.43%	98.13%	99.62%	100%
Confirmed (HIV+)	110 0.03%	170 0.05%	190 0.05%	200 0.05%	171 0.04%	239 0.06%	309 0.07%

Source: AIDS/STI Section, Ministry of Health, Malaysia
Family Health Development Division, Ministry of Health

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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

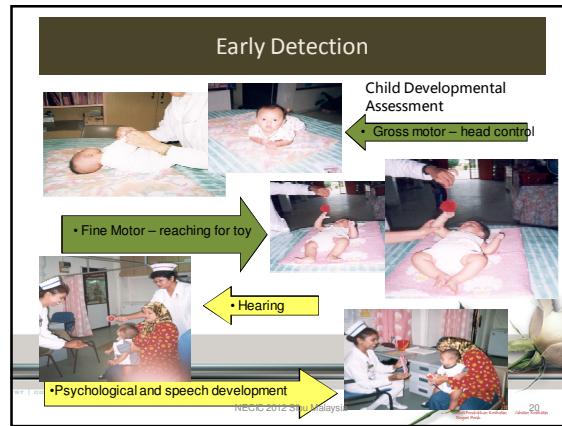
All MUSLIM couples before getting married are required to a 2-days Premarital course. HIV testing certificate required before Nikah.

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PREMARITAL HIV SCREENING								
	YEAR	2005	2006	2007	2008	2009	2010	2011
Total	Number of premarital tested for HIV	45,797	140,980	149,987	186,284	199,202	223,913	248,315
Confirmed (HIV+)	%	67 0.15	144 0.10	103 0.07	262 0.14	105 0.05	146 0.07	219 0.09

Source: AIDS/STI Section, Ministry of Health Malaysia
Family Health Development Division, Ministry of Health

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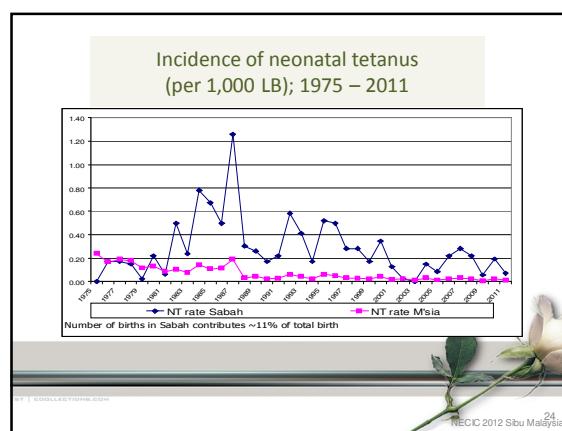
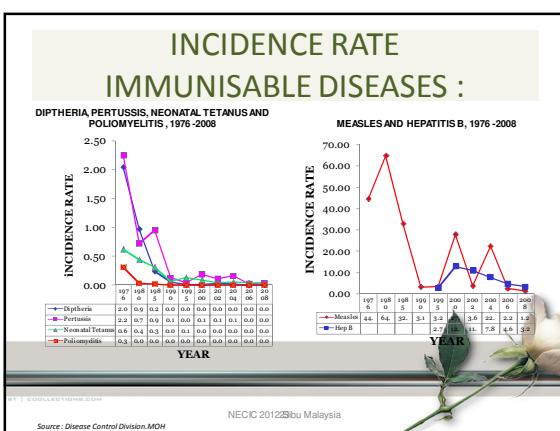


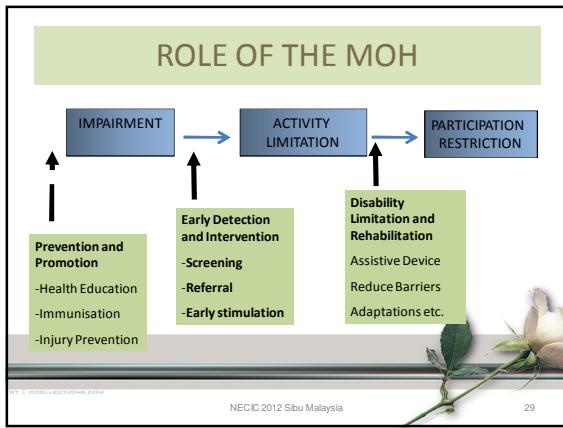
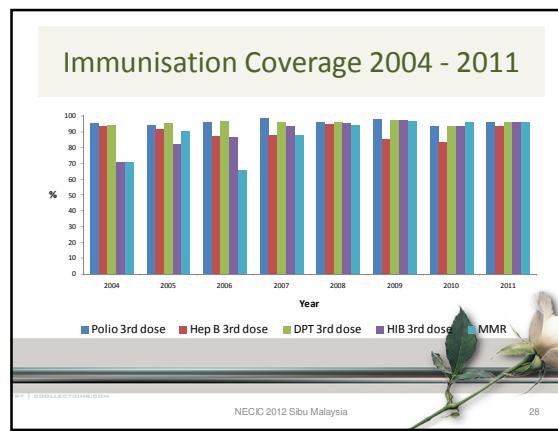
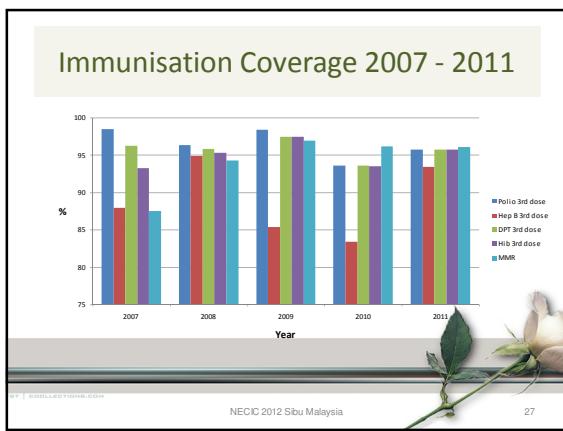
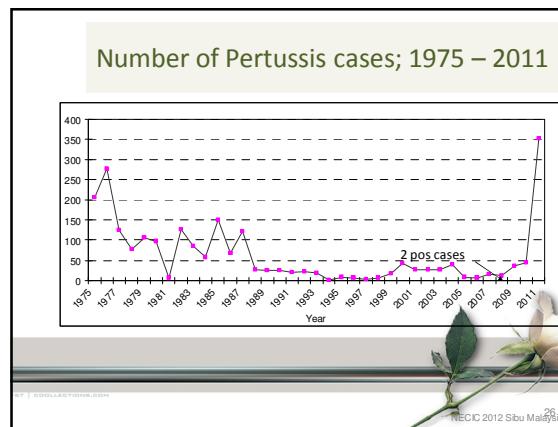
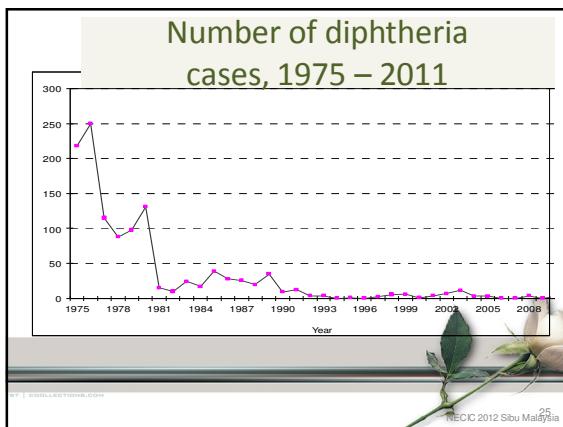
NUMBER OF CHILDREN AGED 0 - 18 YEARS DETECTED ACCORDING TO TYPES OF DISABILITIES FOR THE YEAR 2011													
STATE	Deaf	Blind	Physical	TYPES OF DISABILITIES									Total
				Cerebral Palsy	Deafened	Developmental Delay	Down Syndrome	Autism	ADHD	Neurodevelopmental	Specific Learning	Spastic	
Perlis													
Kedah	3	2	10	7	12	32	2	1	6	1	14	3	171
Penang	29	1	4	12	14	24	18	9	6	25	16	21	279
Perak	7	8	12	9	16	19	22	5	23	61	34	13	229
Selangor	3	2	13	19	54	51	7	13	1	15	25	90	293
JKL	0	0	3	1	1	15	1	1	1	2	3	1	18
W.P Putrajaya	0	0	0	2	0	1	0	0	0	2	3	1	9
N.Sembilan	0	0	3	2	4	12	3	2	0	18	6	32	62
Malacca	4	1	1	1	5	1	1	1	0	13	18	0	51
Sabah	8	2	22	21	35	48	11	1	0	18	38	23	125
Pahang	2	1	15	3	9	17	1	1	0	7	7	10	73
Terengganu	5	1	6	12	14	19	3	1	2	5	12	6	86
Kelantan	2	1	17	13	21	33	3	3	1	1	17	11	121
Sabah	8	3	1	20	1	15	6	5	1	8	8	10	58
Labuan	0	0	2	0	1	5	3	1	5	2	16	1	57
Sarawak	13	4	10	20	54	38	25	12	77	14	36	41	240
Malaysia	73	30	140	157	289	372	114	84	117	239	308	1	2181

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NUMBER OF CHILDREN AGED 0 - 18 YEARS DETECTED WITH DISABILITIES ACCORDING TO AGE FOR THE YEAR 2011 (MALAYSIA)													
AGE	TYPES OF DISABILITIES												
	Deaf	Blind	Physical	Cerebral Palsy	Developmental Milestone	Down Syndrome	Autism	ADHD	Mental Retardation	Specific Learning Disability	Slow Learner	Others	Total
0-1 YR	2	10	43	25	58	220	0	0	0	0	0	76	434
1-2 YR	15	5	46	57	150	76	9	4	2	5	4	77	450
3-4 YR	12	4	13	29	44	34	36	10	7	10	5	60	264
5-6 YR	16	2	11	21	17	18	41	23	19	32	27	35	262
7-12 YR	14	7	19	16	15	18	26	44	70	164	206	53	652
13-18 YR	14	2	8	9	5	6	2	3	19	19	25	7	119
Total	73	30	140	157	289	372	114	84	117	230	207	308	2181

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Disability limitation and Rehabilitation

- Parents

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

- Family

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

- Community

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

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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.



HOSPITAL



HEALTH CLINIC



CBR

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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

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PWD ACT 2008

JK QUALITY LIFE CARE chaired by DG of Health SECTION 33 – 40 OF THE ACT

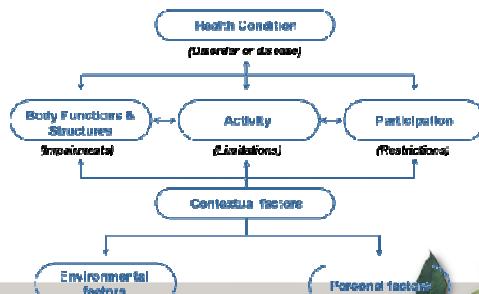
Seksyen	Perkara
33	Habilitasi/rehabilitasi
34	Perkhidmatan di rumah, kediaman & sokongan komuniti
35	Akses kepada kesihatan
36	Pencegahan dan pengesanan awal kecacatan Penggalakan kajian
37	Pengadaan personel kesihatan
38 & 39	Perlindungan orang dengan ketidakupayaan teruk
40	Keadaan berisiko dan kecemasan

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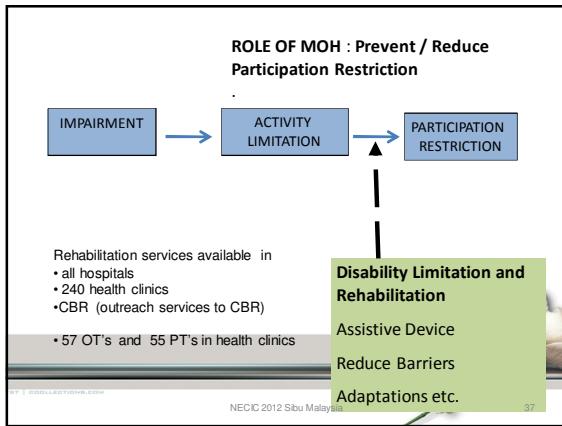
WHO : INTERNATIONAL CLASSIFICATION OF FUNCTIONING AND DISABILITY



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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

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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.

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Resources for Prevention of Blindness

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Resources for Prevention of Deafness

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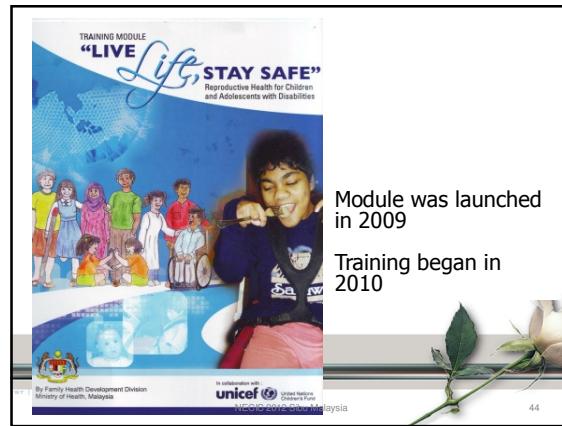
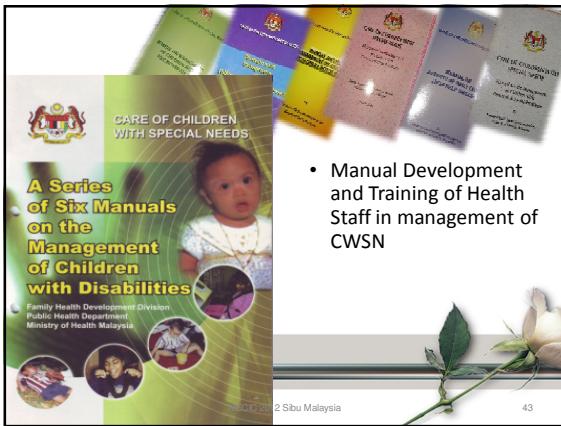
Resources for children with special needs

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3. Training module development

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

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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

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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

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

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

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Future

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

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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

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Acknowledgements

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