

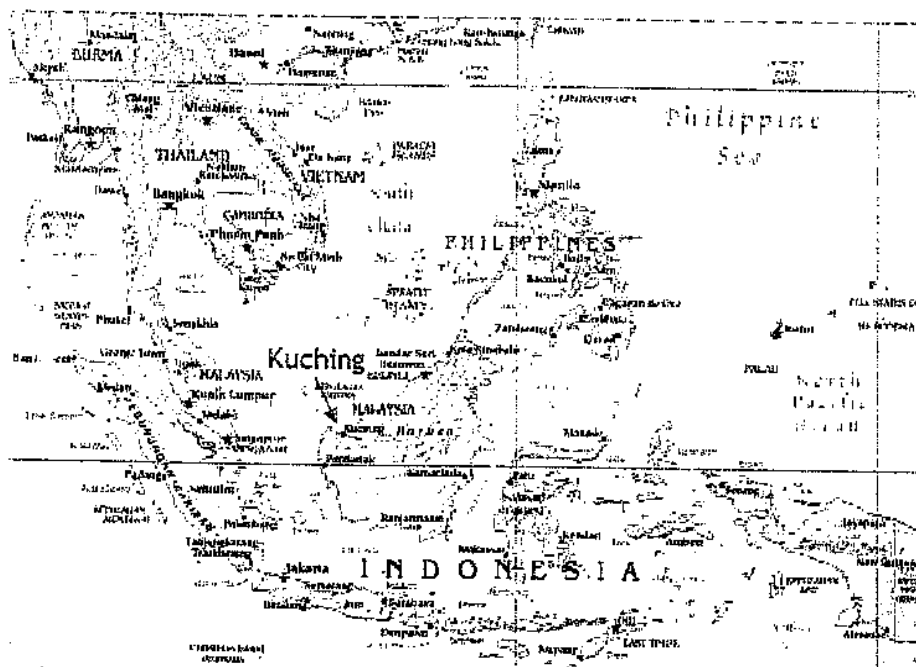


COMMUNITY-BASED REHABILITATION: HEALTHY KUCHING CITY FOR PEOPLE WITH DISABILITIES

1.0. INTRODUCTION: OBJECTIVES AND VISION OF HEALTHY CITY KUCHING

Kuching City joined the Healthy City initiative in 1994. Healthy City Kuching is defined as a "City that enhances the quality of life of its citizens" (see Figure 1 for location of Kuching city). In the Vision Statement for Healthy City Kuching, it was stated that the City "... is blessed with a dynamic and people-oriented society that is caring ..." This is applicable to all citizens, including those with special needs.

One of the approaches which the City uses to enhance the life of people with disabilities and their care-givers is the community-based rehabilitation.



Source of map: http://www.cia.gov/cia/publications/factbook/reference_maps/southeast_asia.html

2.0. WHAT IS CBR

In the ILO-UNESCO-WHO Joint Position Paper, 2002, community-based rehabilitation (CBR) is defined as *"a strategy within general community development for rehabilitation, equalization of opportunities and social inclusion of all children and adults with disabilities."*

An International Consultation to review CBR was organized by WHO, in Helsinki, Finland, in May 2003. The Consultation highlighted that all stakeholders in CBR should work to ensure the human rights of all people with disabilities and multi-sectoral collaboration is essential to CBR, including coordination between community and referral services and among the various referral services.

3.0. INTRODUCTION OF CBR IN MALAYSIA AND KUCHING

An early effort to rehabilitate children with disabilities was initiated in 1972 by the Social Welfare Council of Sarawak. This non government organization (NGO) started a school for the mentally retarded.

The Sarawak Welfare Department had initiated an early intervention programme for children with special needs in 1986.

Community based rehabilitation (CBR), based on the World Health Organization concept, was introduced in Malaysia in 1982. In 1996, Sarawak Health Department established the early detection of children with special needs and clinic-based rehabilitation programme in Jawa Maternal and Child Health Clinic in P. Ramlee Road, Kuching, as part of the expanded scope of the Family Health Development Programme of the Ministry of Health.

Due to limited resources, CBR currently cater to only children (i.e., excluding adults) with special needs.

4.0. AGENCIES INVOLVED IN THE TEAM APPROACH FOR CBR

In Kuching, the care for children with special needs, has been carried out by the government departments as well as NGOs. The government departments include the Sarawak Welfare Department, Sarawak Health Department, and Sarawak Education Department. The NGOs include PIBAKAT (Association of parents of children with special needs), PEKATA (School For

Mentally Retarded Child), SAA (Sarawak Autistic Association), and Sarawak Social Welfare Council.

Even with the contribution of a number of agencies, organizations and associations, existing services for these children in Kuching are still limited. They are provided by in special centres, maternal and child health clinics, in the community, in child care centres, and in schools.

Through CBR, the children are provided with continuous care and activities tailored to meet their needs in order to help them enjoy a better quality of life. Realizing this, a team approach was set up in 1999 for Kuching, focusing on collaboration and coordination between the existing facilities and resources available in order to strengthen the services provided to these children.

5.0. THE NEED FOR CBR

The CBR concept calls for the empowerment of children with special needs and their families, through training and community development. It is hoped that through CBR the children can reach their full potential within their own communities and participate in community life.

The National Health and Morbidity Survey (Malaysia) in 1996 showed that the prevalence of disability among children less than 14 years old was 4.8%. Based on this prevalence, it is estimated that there are more than 32,000 children with disabilities in Sarawak. In Kuching alone, it is estimated that there are approximately 7000 children with disabilities. In contrast, the number of children with disabilities who registered for aid with the Sarawak Welfare Department in 1999, for the whole of Sarawak, was only 856, of whom 523 were from Kuching.

The data available from the health clinics which register these children show even lower figures as they only capture children who have come forward for rehabilitation services in the health clinics. However, reporting has improved since 2003 (see Table 1) with the coordinated reporting by the three government agencies namely: Welfare, Health and Education Departments, using the same reporting format *BPKKK 1 (Pindaan 2003)*. Based on these figures, it estimated that only 2.6% of children with special needs in the state are

receiving some form of rehabilitation service. In comparison, a prevalence of 12.8% of children with special health care needs has been reported in the US¹.

Table 1. Total number of children with special needs registered at the health clinics in Kuching, 2002 - Jun 2005

Year	Number of children
2002	58
2003	88
2004	61
2005 (Jun)	57

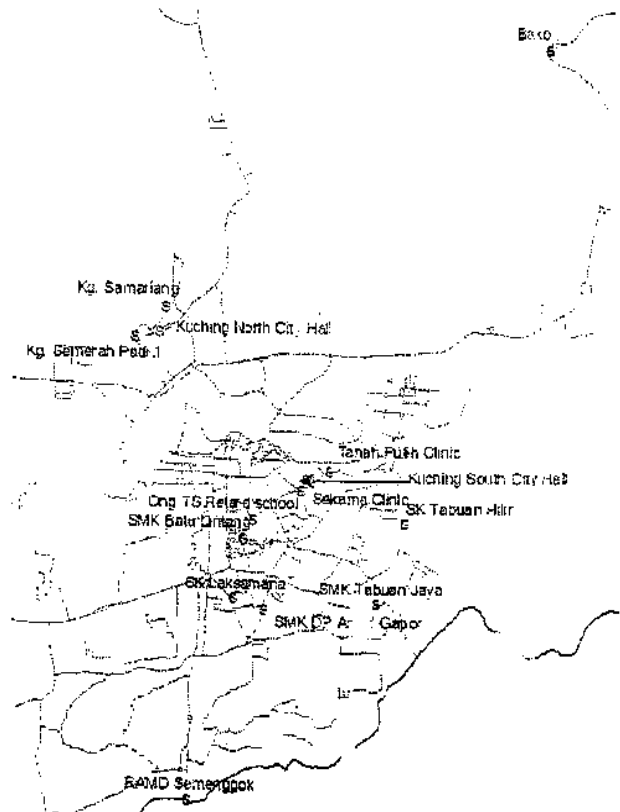
Source: Divisional Health Office, Kuching, Sarawak. 2005

6.0. EXISTING SERVICES FOR CHILDREN WITH SPECIAL NEEDS IN KUCHING, SARAWAK.

The locations of some of the CBR centres in and around Kuching are shown in Figure 2. Brief descriptions of those centres are described below.

6.1. EARLY INTERVENTION PROGRAM (EIP)
 Since 1996, an Early Intervention Program (EIP), has been run by one programme officer from the Sarawak Welfare Department in its EIP Centre at Ong Tiang Swee Road. At the centre, a child is jointly assessed by a paediatrician and the programme officer, after which fortnightly sessions are offered to both child and caregivers for a two-years period. The main problem encountered was a lack of manpower resulting in a long waiting list, which defeated the objective of offering training immediately after detection.

Figure 2: Map of Kuching showing location of CBR centres. Bau lies beyond the boundary of the map.



¹ National survey of children with special health care needs by National Center for Health Statistics of the Centers for Disease Control and Prevention

In April 1999, Sarawak Welfare Department handed over the operations of EIP to PIBAKAT, an NGO, started by parents of children with special needs. However, the Department continues to provide assistance through the use of its premises and provision of support services such as transport, utilities and ancillary staff. The training of three EIP workers has enabled almost 100 children who were initially on the waiting list, to be included in the programme. This centre also serves as a training centre for the staff who work in the Department's CBR centres which are actually located in the community.

The activities carried out at the EIP Centre include: (a) early stimulation programme, (b) play group classes which emphasize learning through play, (c) conducting courses, workshops and seminars, and (d) training parents of children with special needs.



PIBAKAT: Early Intervention Programme Centre, Ong Tiang Swee Road



PIBAKAT: Parents' involvement at Early Intervention Programme Centre.

6.2. CBR CENTRES IN MATERNAL AND CHILD HEALTH CLINICS

A clinic-based rehabilitation programme was started in Jawa Maternal and Child Health Clinic, P. Ramlee Road, Kuching, in March 1996 under the jurisdiction of the Kuching Divisional

Health Office. Within two years, the clinic had registered 124 children with special needs. In those early years, the activities were conducted fortnightly at the clinic and were coordinated by the Medical Officer in Charge of the clinic. Currently, the doctor's session has been increased to weekly clinic due to the high attendances. Since 2005, the clinic also serves as a one-stop referral centre.

The rehabilitation sessions are run by the MCH nurses and public health nurses (PHN) who have basic training in the care of children with special needs. The children are detected and referred from other peripheral clinics, for assessment and further management by the doctor in Jawa Maternal and Child Health Clinic. The activities in the clinic include referral to a paediatrician, schools (education department and PEKATA, the school for the mentally retarded), community-based rehabilitation centres run by the Welfare Department (PDK), physiotherapy and occupational therapy. An individualized care plan is formulated after joint discussion with all team members which include the doctor, nurses, parents, physiotherapist and occupational therapist.

Activities at Jawa MCH



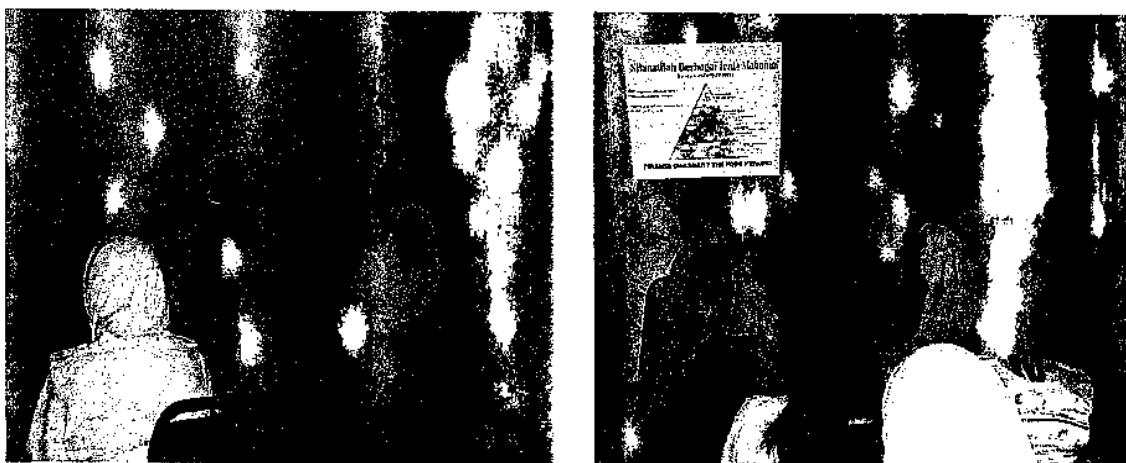
Jawa MCH: Rehabilitation area. The clinic was also used as a training center for physiotherapist and student nurses. Parents' involvement in intervention activities.

Since 2005, under the guidance of the Kuching Divisional Health Office and with one permanent physiotherapist, the program has been extended to other Maternal and Child health clinics in Gita, Tanah Puteh, Sekama and 10th Mile. All these clinics have been equipped with rehabilitation equipment.

Early child and infant development and stimulation activities were introduced in 2005 to all of the clinics involved in the rehabilitation program. The staff and parents were trained to do the early stimulation activities.



Jawa MCH: Child assessment day. Also present are PIBAKAT member (parents' association of handicapped children) who help during this day.



MCH Jawa: Regular health talk to empower staff and parents on the care for children with special needs.

6.3. SCHOOL FOR MENTALLY RETARDED (PERKATA)

PERKATA was initiated in 1972 by an NGO, the Social Welfare Council of Sarawak. It caters for children who are mentally handicapped and with learning disabilities from the age of 7 onwards. In 1999, it employed 11 special education teachers to teach the 152 students at the school.



PERKATA: School for mentally retarded



PERKATA: The cerebral palsy class



PERKATA: Ordinary class



PERKATA: Learning to measure



PERKATA: Eye screening for student conducted by a team from the Eye Clinic, Sarawak General Hospital and MCH clinic, using Gardner Sheridan Chart.



This school also provides a pre-school class, also called the early intervention programme. This service offers pre-school experience to special needs children. The original aim was to fill the gap between the Welfare Department's EIP and the primary schools of the Education Department. Children from the age of five years are accepted into this preschool.

6.4. COMMUNITY BASED REHABILITATION CENTRES RUN BY SARAWAK WELFARE DEPARTMENT

The Welfare Department has established real community-based rehabilitation centres for persons with special needs. Currently there are 11 such centres in Sarawak with a total staff strength of 30. Three of the centres are in Kuching district.

6.4.1. PENRISSEN CBR

The Welfare Department initiated this CBR centre in Penrissen Army Camp which is now self-running. The centre has two trained staff and one trainee volunteer who run training sessions for 37 children, with ages ranging from 9 months to 22 years. Regular training and supervision of staff is provided by the Welfare Department.



Penrissen CBR: One-to-one therapy, and group therapy.

6.4.2. PETRA JAYA CBR

This centre was opened in 2001 and has two staff. It is situated in Kampung Semariang which is a Malay village in Petra Jaya. It runs everyday from 9:00 am to 12.30 pm. It has 38 registered children. On Wednesdays, nurses from Malaysia Jaya MCH Clinic go to this centre to do the early stimulation activities.



Kampung Semariang, Petra Jaya CBR: Involvement of parents in their children's activities.

6.4.3. BUNTAL CBR

Buntal CBR was opened in 2004 and has 18 registered children. The centre is temporarily operating at private house. The committee members comprises the village head man, parents, a representative each from the Welfare Department, Health Department, and Education Department, and KEMAS (a community development programme of the Ministry of Woman, Family and Community Development). The activities are conducted everyday, and they include home visits.

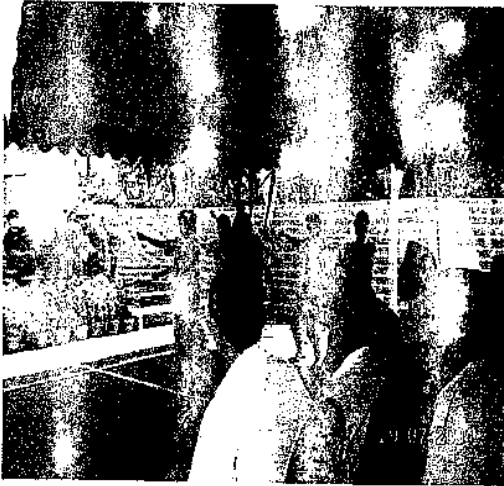
The centre is visited regularly by physiotherapists and an occupational therapists from Sarawak General Hospital, doctors, and parents support groups.



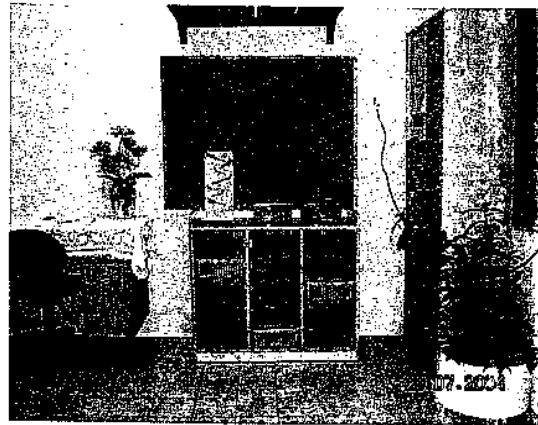
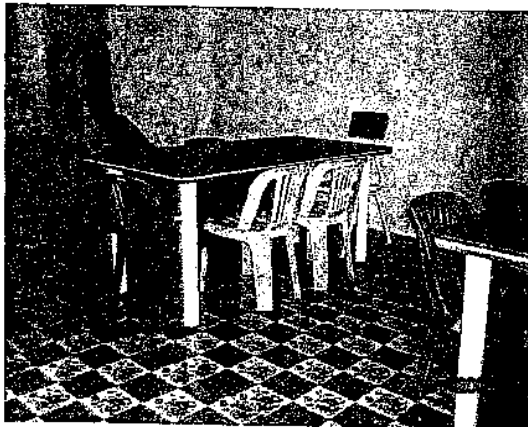
Buntal CBR: Visiting physiotherapist and occupational therapist from Sarawak General Hospital. The parents are taught on the proper ways of handling children with special needs.

6.4.4. BAU CBR

Bau CBR was officially opened in 2004. However, the rehabilitation programme for children with special needs in Bau had been carried out since 1996 in the maternal and child health clinic in Bau Hospital. In 2004, Sarawak Welfare Department opened a CBR and the hospital-based rehabilitation programme was then moved to this new centre. Currently, the centre has 60 registered children.



Opening ceremony of Bau CBR: Performance by children with special needs.



Bau CBR: Some facilities available at the centre

6.5. PRE-SCHOOLS FOR CHILDREN WITH SPECIAL NEEDS.

Currently, there are eight private pre-schools or nurseries which accept children with special needs in Kuching. They are Chin Chin, Intan, Montesori, Woodland, Kinderland, Bako, Milestone and Tree House. In 2005, the Education Department opened one preschool class in Semerah Padi school in Petra Jaya, Kuching.

6.6. SARAWAK AUTISM ASSOCIATION (SAA)

Sarawak Autism Association was formed in 1998 by a group of parents of autistic children and professionals. The association runs awareness campaigns on the needs of autistic people. Initially it started a class at the PIBAKAT EIP centre but now runs a school at a rented house with four teachers and 11 students. Morning and afternoon sessions are conducted from Mondays to Fridays. Without any established financial grant from the government, the fee charged is RM 200 per child monthly to meet its high operating cost of one-to-one teaching method. It hopes to increase access to the lower income groups when its financial situation permits.

6.7. SCHOOLS FOR CHILDREN WITH SPECIAL NEEDS

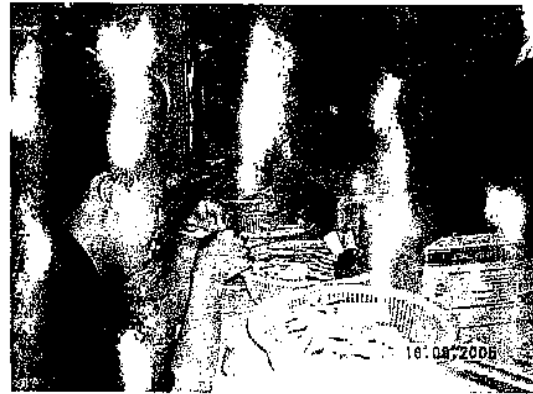
Children with special needs must register with the Education Department by the age of 7 years to 14 years for primary school enrolment and 15 to 19 years for secondary school enrolment. In Kuching, there are 8 primary schools and 5 secondary schools provided integrated program. The names are listed in Table 1.

Table 1: Primary and secondary schools with classes for children with special needs

Primary schools	Secondary schools
1. Tabuan Ulu	1. Tabuan Jaya
2. Astana	2. Bako
3. Laksamana	3. Baru
4. Semerah Padi	4. Batu Lintang
5. Combined	5. DPHAG, Stampin
6. Tabuan Hilir	6. Special Education School (Deaf)
7. Semenggok	7. Special Education School (Blind)
8. Tan Sri Rahman	

6.8. ONG TIANG SWEE ROAD CBR

The CBR at Ong Tiang Swee Road, is a day training center for young adults (18 years and above) who are intellectually disabled.



CBR center: work skills e.g., doing packaging for KFC restaurant.

7.0. MEASURING SUCCESS.

There is no easy way to measure success of these rehabilitation programs. For parents of children with special needs, their life now become much easier with the availability of the following services:

7.1. Implementation of one-stop referral center in the Maternal and Child Health clinic at P. Ramlee Road. The activities in this one-stop referral centre include:

- a) Assessment of children in order to develop a personalized intervention and care plan and to measure the progress made by the children undergoing the intervention.
- b) Early diagnosis and treatment made by medical officers and paediatricians who run the clinic weekly on Thursday afternoons.
- c) Early referral for rehabilitation to physiotherapists, occupational therapists, and speech therapists who run their sessions at the clinic.
- d) Early referral to relevant specialists in Sarawak General Hospital; a special arrangement was made between the Clinic and the respective units in the hospital especially the ENT, paediatrics and child psychiatric units, to cut down waiting time.

- e) Referral to community based rehabilitation centre run by the Sarawak Welfare Department, and early intervention centre; such referrals are made even easier when the staff from those other centres also attend the doctors' sessions.
- f) Referral to schools for children at the age of four years old, either to education department (integrated class or special education for deaf and blind children) or school for mentally retarded.
- g) Referral to other departments such as the Sarawak Welfare Department, and so on.
- h) Assessment centre for children with specific learning disorder, which started in 2005.

7.2. Community development.

- a) Participation of the local people in the care for children with special needs was encourage through regular meetings and discussions, talks, open days and involvement in charity fund raising activities.
- b) In 2005, a parents' support group was formed specially to provide emotional and social support to the parents.

7.3. District level committee.

- a) This committee has regular meeting at least once a year to discuss any problem arising. The members include doctors and other staff from the Sarawak Health Department, officers from Sarawak Welfare Department, an education officer in charge of special education, PIBAKAT (parents association), principal of the School for Disabled Children, and staff and nurses from community-based rehabilitation centres and other clinics.

7.4. Increase number of school and private nurseries for children with special needs.

- a) The number of schools with special classes for children with special needs has been increasing in the past five years. The fact that more students are able to enroll directly in those schools showed the success of early intervention programmes, and especially so if the children are able to score well during exams (which some of them did).
- b) The existence of private nurseries that offer care of these children also show the changes in attitude towards these children where their special needs were recognized and acknowledged, and their presence in the community were easily accepted.

8.0. CONCLUSION AND FUTURE NEED.

As the children grow, their needs also grow. In Kuching, the development of preschool, schools and vocational training for these children is still far from satisfactory. The shortage of specialists in certain professions, inadequate training programmes, insufficient knowledge and awareness have to be addressed.

There are many challenges ahead as we try to meet the needs of these children, their parents and other care givers. A statewide comprehensive service can become a reality only if there is a pooling of existing resources and a commitment to develop resources in this specialized area. The existing network of resources should be optimally coordinated and shared to its maximal potential. Central to the planning process is the voice of parents and the needs of their children as a partner in decision making. With a greater understanding of community based rehabilitation, service development across sectors will be more comprehensive and most importantly, reach all layers of society and those most in need.

Government agencies and NGOs need to pool their resources, knowledge and skills into a systematic team in order to reach people with disabilities and their caregivers within their communities to ensure that the maximum number of children can be reached when they most need it and to where they most need it. One of the goals in provision of health services for children with special needs is to screen children early and continuously for special health care needs. When sufficient resources and skills can be developed, the multi disciplinary approach to management of the children with special needs can be further decentralized for greater accessibility to the caregivers.

We need for more specialized training to all the personnel involved in this programme especially in behaviour therapy which play a very important part as the children grow. Behaviour therapy is also very important in cases like autism, Down's syndrome and other mental handicaps. Facilities for vocational training for the older children are still very lacking.

Group-homes will be necessary individuals with special needs whose parents or guardians have departed. If we do not look into this problem seriously, the cases of homeless individuals will become a major issue.

In Kuching City, we can see marked improvements in the coordination and sharing of expertise over the past three years. A dedicated team which we have now will make sure our children with special needs will get the care and love that they deserve.

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