

UNIT NO. 4

REHABILITATION AND COPING WITH DISABILITIES IN CHILDREN AND INFANTS

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ABSTRACT

Children with disabilities should have appropriate rehabilitation. Early rehabilitation has been shown to improve functional outcome. An interdisciplinary team of doctors and allied health workers should manage the rehabilitation programme. The programme should be goal oriented and based on real world demands. Any rehabilitation intervention should involve the family so as to reduce stress and improve compliance and then, function. The child should be integrated into community services for more ongoing rehabilitation in a school-based structure.

SFP2007; 33(3)Supplement: 24-27

INTRODUCTION

There are approximately 60,000 disabled children less than 18 years of age in Singapore. They are either physically handicapped, visually handicapped, hearing impaired, cognitively handicapped or have a combination of these disabilities. Rehabilitation is important as a form of intervention to improve functional outcome. Rehabilitation should begin as soon as disabilities are expected or discovered. Intervention should be an interdisciplinary team effort with the emphasis on setting goals and working towards them.

In the development and implementation of any intervention and rehabilitation programmes for children with disabilities, the government of Singapore's philosophy is that these children should have the opportunity to achieve their potential and be independent where possible, to be integrated into society where feasible and practical, to be encouraged to live within the community as far as possible and admission into institutions should be the last resort.

Examples of these interventional programmes are the early intervention programme, integrated childcare programme, WeCAN early intervention programme, and brain injury rehabilitation programme at KK hospital, special education schools, vocational institute and sheltered workshops.

The approach to rehabilitation of a child with disabilities begins with an extensive surveillance and assessment programme, systematic interdisciplinary therapy and proper use of community service to place these children with ongoing rehabilitation.

ASSESSMENT OF DISABILITIES

An assessment of a child's disability is to systematically collect, organise and interpret information about the child and his situation.

Before any form of rehabilitation intervention can be introduced, a thorough and complete assessment of the child's disability should be done. This assessment should be continued at regular intervals throughout the child's development to provide feedback to the rest of the team and to review the response to the intervention.

A complete assessment should include the following:

1. A definition of the child's impairment and problems
2. An evaluation of the genetic, biological, environmental and pathological factors which contribute to the problem
3. An estimate of the child's current development status
4. Hearing and vision screening
5. An extensive evaluation by physiotherapist, occupational therapist, speech and language therapist and if necessary, to perform any psychometric test for behavioural and cognitive assessment

All these should lead on to organising the most appropriate intervention programme for the child to manage his impairments.

In Singapore, we have in place a 0-5 years of age child development evaluation programme which screens and assesses >90% of the population. This programme is in place in all polyclinics, paediatricians in both the public and private sector use it and a brief questionnaire in all health booklets allows parents to pick up any developmental problems. Within the hospital, the neonatal department and child development unit have programmes that screen and follow up babies with brain injury or genetic predisposition to develop developmental problems and disabilities.

The Denver developmental assessment test is one of the screening tools that is commonly used by the maternal and child health service to do developmental surveillance. This surveillance and monitoring instrument is employed by professionals or trained paraprofessionals to determine if a child's development is within the normal range. It is a useful instrument for identifying children at risk. The results are not diagnostic. It is to be used with children from birth to six years of age.

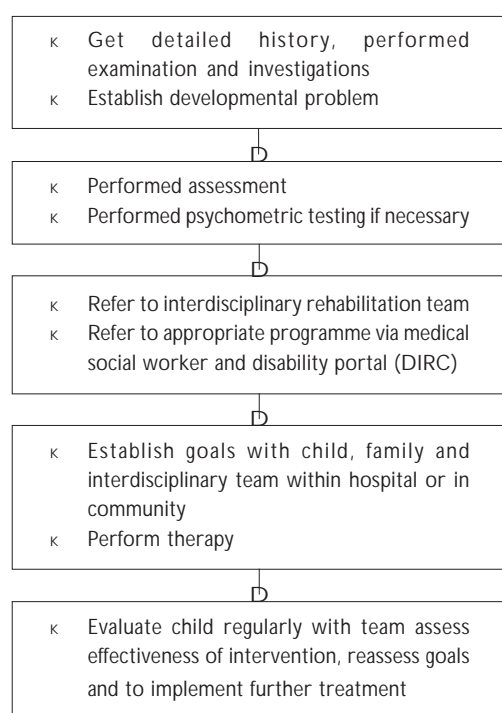
THE INTERDISCIPLINARY THERAPY TEAM

All rehabilitation programmes should have an interdisciplinary team assigned to it. Interdisciplinary rehabilitation as compared to multidisciplinary rehabilitation has shown to improve

outcome in all forms of rehabilitation. The element of an interdisciplinary model is that everyone in the team knows the main principles of interdisciplinary teamwork, the scheme of the rehabilitation process, and has the same terminology of the impairments and disability of the child as the common conceptual framework.

Implementation of the interdisciplinary model has meant a clear understanding of each professional's own viewpoint and limitations regarding the child's impairment and disability, then, working towards a similar goal to improve on the child's function. Therefore, this is a more structured and qualitative way in which providers help the child during the rehabilitation process.

Figure 1. Approach to the Child with Disability



MEMBERS OF THE REHABILITATION TEAM

A case manager or paediatrician with interest in development, rehabilitation or neurology should take charge of any intervention programme so as to provide regular assessment and setting goals with the other team members, using regular case discussions or specialised clinics. The other team members are made up of allied health workers such as physiotherapists, orthotists, occupational therapists, speech and language therapists, special education teachers or therapists, clinical or neuro-psychologists and social workers, as well as other doctors who may contribute to the well being of the child, such as paediatric orthopaedic surgeons, paediatric ophthalmologist, paediatric ENT specialist, etc. These interdisciplinary teams are either formed within the hospital for early intervention, post brain injury rehabilitation and specific disability intervention, or in the community setting within the various special schools in Singapore.

Physiotherapists focus on gross motor skills and functional mobility, including:

- positioning;
- sitting;
- transitional movement, such as sitting to standing; walking with or without assistive devices and orthosis or prostheses;
- wheelchair propulsion;
- transfers between the wheelchair and other surfaces such as bed, toilet, and bath;
- negotiation of stairs, ramps, and curbs; and
- problem-solving skills for accessibility of public buildings.

Orthotists measure and make orthotic devices for motor impaired children, for aid in ambulation or to prevent abnormal postures or contractures.

Occupational therapists focus on fine motor, visual-motor and sensory processing skills needed for basic activities of daily living such as eating, dressing, grooming, toileting, bathing, and written communication, like writing or keyboard skills. They train school related skills and strategies to help these children compensate for specific deficits.

Speech and language therapists address speech, language, cognitive-communication and swallowing skills in children with disabilities. They can source and prescribe augmentative alternative communication devices to aid communication.

Neuropsychologists perform psychometric testing to assess the cognitive and behavioural function of the cognitively and socially impaired children. Psychometric tests are any systemic procedure for observing a person's behaviour and describing it with the aid of a numerical scale or category scale.

Special education therapists are those with specific skills to work with specific disabilities in children such as teaching of Braille, Paget-Gorman sign language, working with Autistic children, providing music and art therapy.

PRESCRIBING THERAPY

The doctor's or case manager's role in prescribing therapy includes providing an accurate diagnosis when possible, providing an accurate description of the medical condition and noting whether the child has a transient, static or progressive impairment. A care plan must be recommended if the child has other medical co morbidities. The type, frequency and duration of therapy should be made known and goals should be designated. These goals are most appropriate when they address the functional capabilities of the individual child and are relevant to the child's age-appropriate life roles such as school, play and work. The doctor should also work with the family, child, therapists, school personnel, developmental diagnostic or rehabilitation team and other physicians to establish realistic functional goals.

EARLY INTERVENTION PROGRAMME

The rate of human learning and development is most rapid in the preschool years; hence the timing of intervention becomes particularly important when a child runs the risk of missing an opportunity to learn during a state of maximum readiness. Intervention should begin early because this enhances the child's development, provide support and assistance to the family and it maximises the child and family's benefit to society.

Early intervention refers to services that are delivered to children from birth to three years of age, who are discovered to have or to be at risk of developing a handicapping condition or other special need that may affect their development. Early intervention focuses on remedying existing developmental problems or preventing their occurrence. This enables the child to live to the maximum of his potential and is able to participate fully in society. Early intervention services should focus on the child and family together. It can be home based, hospital based or centre/school based, or a combination.

Early intervention is effective, as 50 years of research has shown it to increase the developmental and educational gains for disabled child. These children will need fewer special education and other rehabilitative services later in life, being retained in grade less often and in some cases being indistinguishable from non-handicapped classmates.

Early intervention services also have a significant impact on the parents and siblings of a developmentally delayed infant or young child. The family often feels disappointment, social isolation, added stress, frustration and helplessness. This compounded stress on the family can also affect the child's development. Families with handicapped children are found to have increased risk of divorce, suicide and a handicapped child is more likely to be abused. Family intervention results in parents having improved attitudes about themselves and their child, improved information and skills for teaching their child and more release time for leisure and employment. As explained later, many organisations that provide early intervention programme have good parental support services too.

MEASUREMENT OF OUTCOME

Improvement in function is more likely to occur when goals of therapy are specific and measurable, and established in partnership with the child's parents and other caregivers.

The doctor can assist families in identifying the short-and long-term goal of treatment, establishing realistic expectations of therapy outcomes, and understanding that therapy will usually help the child adapt to the condition but not change the underlying neuromuscular, neuro-cognitive or behavioural problem.

The Gross Motor Function Classification System is used to follow the natural course of a child with motor impairment, to assess their severity, and enable the rehabilitation team to grade the child's abilities and prognosis. Paediatric Evaluation of Disability Inventory (PEDI) is designed for the functional

assessment of children between six months and seven years of age. It measures the child's capability and functional performance in self-care, mobility, and social function. The Functional Independence Measure (FIM) for adults and children >7 years of age, and the Functional Independence measure for Children (weeFIM) for children six months to seven years of age measure 18 items related to independence in daily functions including self-care, sphincter control, mobility, locomotion, communication and social cognition. These tools are often used to assess children's functional and motor outcomes to guide the rehabilitation team in therapy prescription.

COMMUNITY REHABILITATION AND SUPPORT

Voluntary Welfare Organisations (VWOs) run 21 Special Education (SPED) schools in Singapore. They are the Asian Women's Welfare Association (AWWA), Association for Persons with Special Needs (APSN), Movement for the Intellectually Disabled of Singapore (MINDS), Rainbow Center, Spastic Children's Association of Singapore (SCAS), Metta Welfare Association, Presbyterian Community Services, Autism Resource Centre, Autism Association, Cannossian Daughters of Charity, Singapore Association for the Deaf and Singapore Association of the Visually Handicapped.

They provide the community support for ongoing therapy for children with disabilities. Many of these schools are equipped with physiotherapists, occupational therapists, speech and language therapists, special education teachers and social workers. Together they provide weekly therapy sessions incorporated into a school schedule. This allows the children to have some social interactions and the parents/carers, some respite. Many of these organisations have specific interventions for example AWWA special school. They provide an Early Intervention Programme for Infants and Children (EIPIC) and Programme for Children with Multiple Handicaps (PCMH). In 2001, the school started 'Project Challenge' which is for children with autism and behavioural concerns. They also have a TEACH ME project that provides physiotherapy, occupational therapy, and tuition to disabled children who are attending mainstream school.

Referrals to these VWOs can be made directly or through the disability portal. The Disability Information and Referral Centre (DIRC) is a non-profit organisation run by the Society of Moral Charities (SOMC) and funded by the Ministry of Community Development, Youth and Sports (MCYS). DIRC is more than a resource centre. It provides one-stop service for information and resource support to persons with disabilities, persons seeking information on services for the disabled, caregivers, service providers and people working in the disability sector and the public. On 15 March 2006, DIRC became the **Central Referral Agency** for the Homes for Adults with Disabilities, Day Activity Centres (DACs), Early Intervention Programme for Infants and Children (EIPIC) and Integrated Child Care Programme (ICCP).

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LEARNING POINTS

- o Rehabilitation is important as a form of intervention to improve functional outcome.
- o Rehabilitation should begin as soon as disabilities are expected or discovered. One of such rehabilitation is the Early Intervention Programme for Infants and Children (EIPIC).
- o All rehabilitation programme should have an interdisciplinary team assigned to it as this has shown to improve outcome.
- o Rehabilitation for children with disabilities in Singapore should be both hospital/clinic based and with the support of community services.