

ABSTRACT

Rehabilitation of infants and children with disabilities focuses on enhancing their abilities to perform tasks and participate meaningfully in everyday activities. The International Classification of Functioning, Disability and Health (ICF) provides a rehabilitative model which characterises the child's functioning and health in the context of relevant personal and environmental factors that can facilitate or hinder performance. Using the ICF framework, the general principles of rehabilitating infants and children with disabilities are: 1. Family-centred care with effective communication and collaboration of members within the multi-disciplinary team; 2. Address fundamental needs of a growing infant and child; 3. Intervention to improve body functions and structures; 4. Encourage participation in patient and family meaningful activities. The primary health care provider plays an integral role in managing infants and children with disabilities.

Keywords: Rehabilitation, Disability in infants and children

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INTRODUCTION

Paediatric rehabilitation involves caring for children from birth through 21 years of age with both congenital and acquired disabilities and helping them achieve their greatest functioning potential. Strictly speaking, by definition, rehabilitation is the process of restoring a person with a disability to the fullest physical, mental, social, vocational, and economic usefulness that the person is capable of. It typically refers to the effort to restore former capacity.¹ This contrasts with the term 'habilitation' which is the process of developing a skill to be able to function in an environment. It implies development of abilities not previously mastered² and therefore, would be the appropriate term to use in managing children with congenital disorder who have yet to achieve most milestones. However, regardless of the origin of disability, using the term rehabilitation to refer to both rehabilitative and habilitative services is common practice, given that both processes have the same ultimate goal of optimising the functioning of the child with a disability. This article aims to outline the general principles of rehabilitation of infants and children with disabilities and the role of a primary health care provider in the management.

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THE ICF AS A FRAMEWORK IN PAEDIATRIC REHABILITATION

The World Health Organisation's International Classification of Functioning, Disability and Health (ICF) offers a framework for a holistic, multi-disciplinary and goal-oriented team approach in paediatric rehabilitation.³ It includes the three domains of Body Functions and Structures, Activities and Participation, complemented by the contextual elements of Environment and Personal Factors (refer Figure 1). This revised ICF model views disability more than just a medical phenomenon but also emphasises the impact of disability on an individual's functioning and life experience. The goal of management, in this framework, is participation, acknowledging that optimal involvement in life situations is what truly matters. The ICF is particularly useful in conceptualising ways in which children can achieve their goals and do what they find meaningful. Refer Figures 2-4 for examples of how this model can be applied in rehabilitation of a child with cerebral palsy, Duchenne muscular dystrophy and spina bifida respectively.

GENERAL PRINCIPLES OF PAEDIATRIC REHABILITATION

With the ICF model in mind, the general principles of rehabilitation of infants and children with disabilities are:

- 1) Family-centred care in a multi-disciplinary team
- 2) Address fundamental needs of a growing infant and child
- 3) Intervention to improve body functions and structures
- 4) Encourage participation in patient and family meaningful activities.

FIGURE 1. THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (ICF).

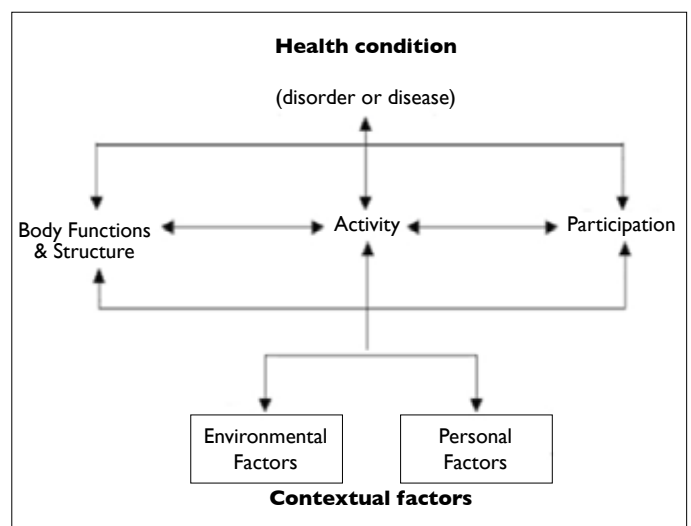


FIGURE 2. APPLICATION OF THE ICF TO A CHILD WITH CEREBRAL PALSY.

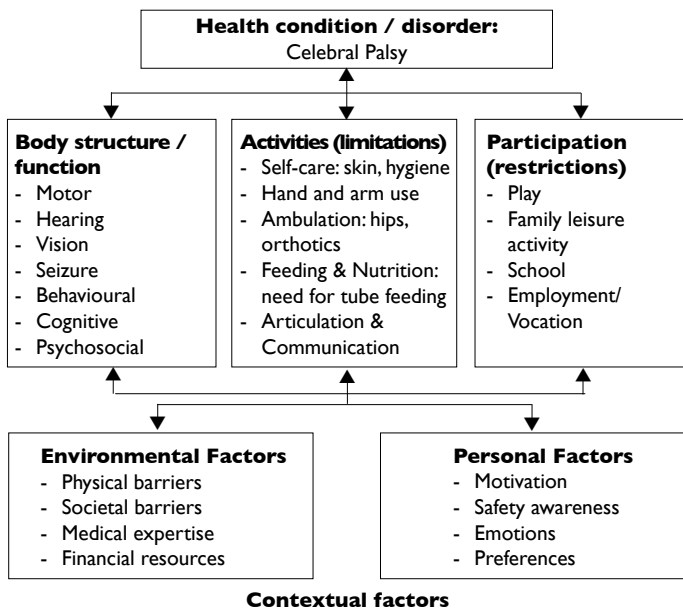
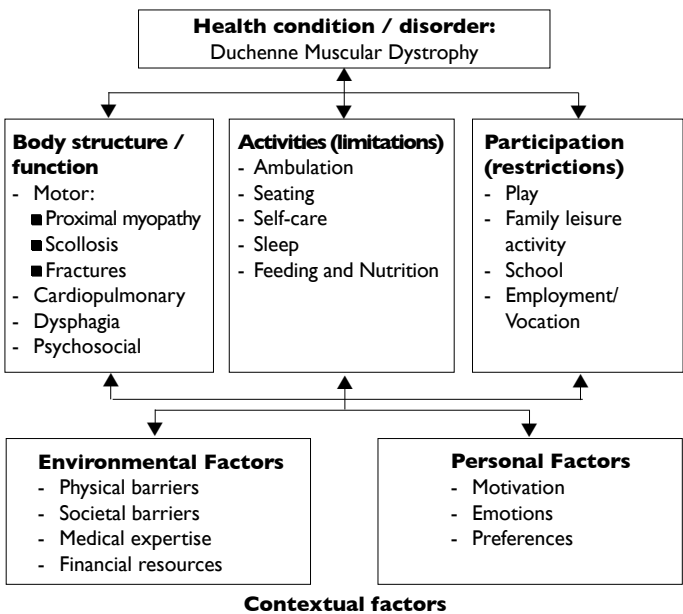


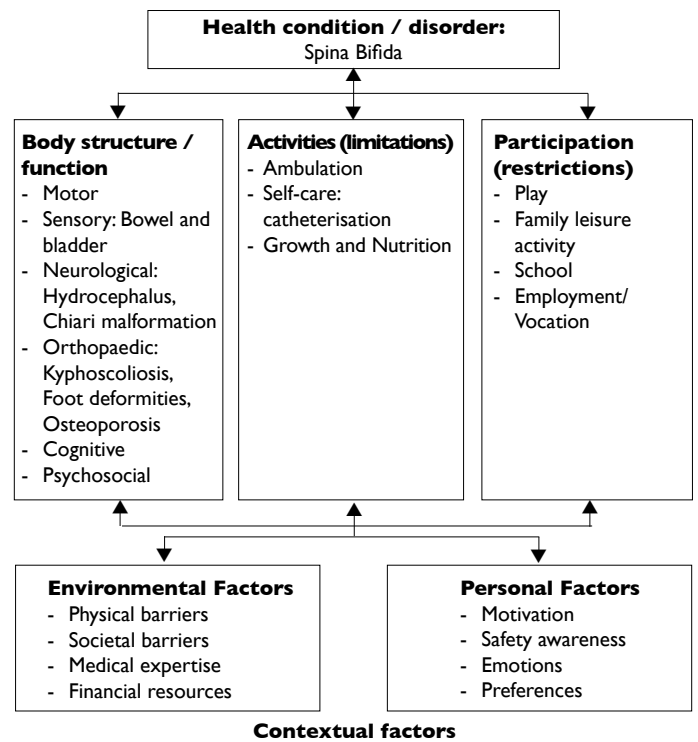
FIGURE 3. APPLICATION OF THE ICF TO A CHILD WITH DUCHENNE MUSCULAR DYSTROPHY



Family-centred care in a multi-disciplinary team

Family-centred care is a fundamental approach to management of children with disabilities. Family-centred care refers to how health care professionals interact, provide services and involve patients and their family in their care.⁴ The key elements of family-centred practice include an emphasis on strengths of the child and the family, facilitating informed choice by family and creating a therapeutic environment that optimises the development of a collaborative family-health care provider relationship.⁵ Family-centred care is about providing appropriate information and support, and enabling family empowerment and engagement.

FIGURE 4. APPLICATION OF THE ICF TO A CHILD WITH SPINA BIFIDA



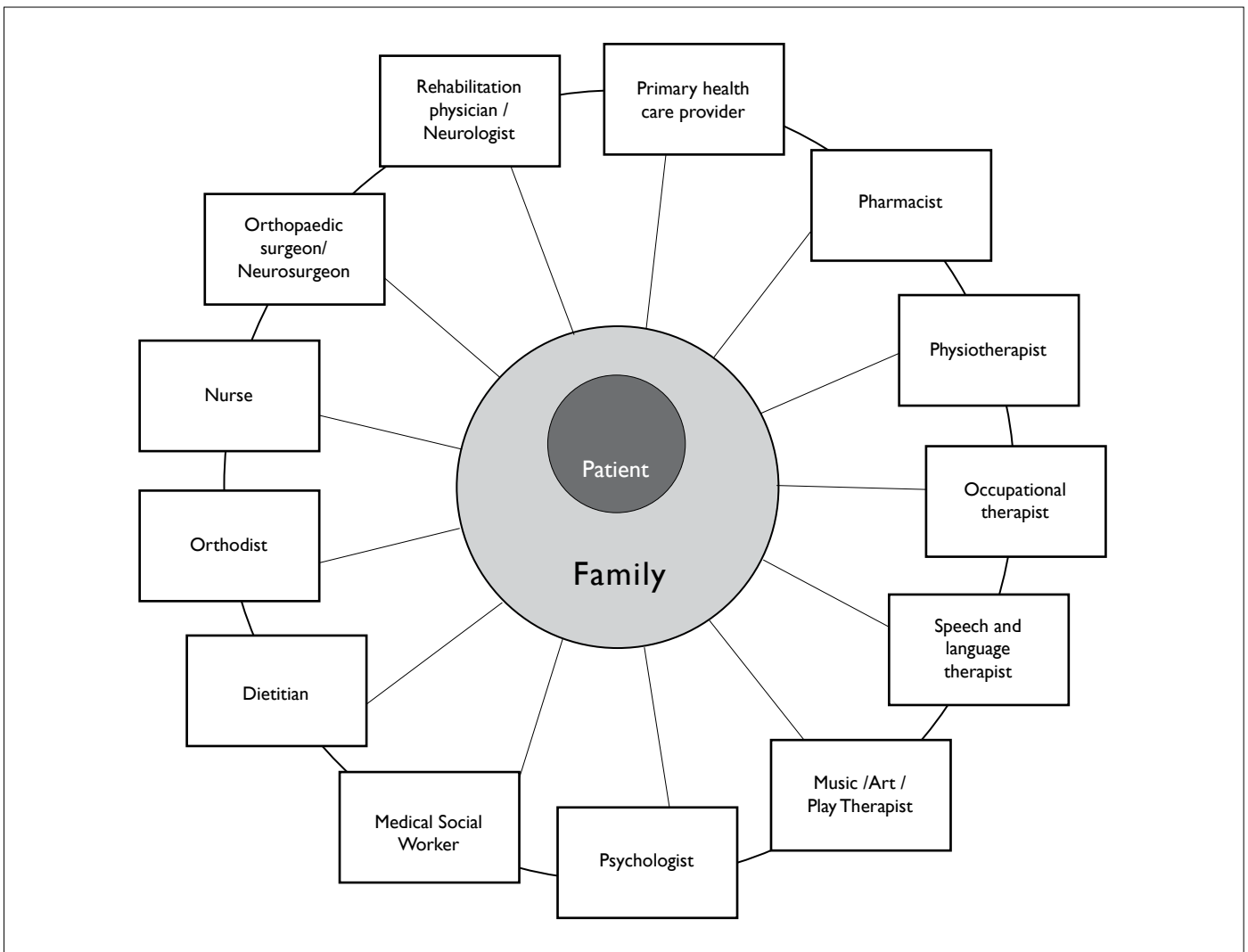
With this approach, it makes care coordination and collaboration within the multi-disciplinary team even more vital. The team comprises of the primary health care provider as well as specialists in Neurology, Orthopaedics and Neurosurgery, working in conjunction with therapists, nurses, dieticians, pharmacists, psychologists, social care providers and school teachers. After helping the family to prioritise and identify meaningful key outcomes, there must be effective communication between the different services and disciplines within the team so that all team members can focus in helping the patient and the family towards a common goal (refer Figure 5).

Address fundamental needs of a growing infant and child

Rehabilitation of infants and children with disabilities involves addressing all developmental aspects of the child and planning timely interventions with regards to the most urgent needs of the child and the family. The members of the multi-disciplinary team, including the primary health care provider, should have a good knowledge of childhood developmental milestones and an adequate understanding of the basic needs of a child including growth, nutrition, vaccinations and education.

Due to inter-current illness, some children may slip through the cracks of the well child system and fall behind in immunisations. Due to their particular susceptibility to infection, the primary health care provider should make sure that pneumococcal and influenza vaccinations are given routinely to this group of children.

FIGURE 5. THE CORE MEMBERS OF THE MULTI-DISCIPLINARY TEAM OF REHABILITATION OF INFANTS AND CHILDREN WITH DISABILITIES.



While vocational rehabilitation is an important consideration for the adult with a disability, special education is important to the child with a disability. Before the age of seven, children with physical disability, sensory impairment or other disabilities are referred to special education centres for early intervention upon diagnosis. There are 17 Early Intervention Programme for Infants and Children (EIPIC) centres run by 10 voluntary welfare organisations (VWOs) in Singapore. Together with KK Women's and Children's Hospital (KKH) and National University Hospital (NUH), these centres cater to infants and children who require specialised help such as speech, occupational and physical therapy (refer Figure 6).

After the age of seven, depending on the degree of the disability, some children may be able to cope with parts of the mainstream school curriculum with additional support, while others may benefit more from special curricula taught by suitably-qualified teachers in Special Education (SPED) schools that are operated by VWOs, with the support of the Ministry of Education and the National Council of Social Service. The aim of all SPED schools is to develop each child's capacity to his fullest potential, with the long-term objective of enhancing his

prospects of integration into mainstream society.⁶ The education curriculum is supplemented with rehabilitative services which enhance the child's well-being and all-round development.

Intervention to improve body functions and structures

Specific areas of concern should be looked into, depending on the specific medical condition. These may include management of motor, sensory, neurological, cognitive and psychosocial complications.

A. Motor

In neuromuscular diseases, issues of spasticity and orthopedic conditions of contractures, scoliosis and hip dysplasias have to be monitored and managed accordingly.

If motor limitation exists, adaptive devices may be used. When the skills of eye-hand coordination and safety awareness are acquired, the child may be able to control a wheelchair with a joystick. For the child with ambulation potential, lower extremity orthotics provide support and improve gait efficiency, while walking aids may provide added stability and prevent falls.

FIGURE 6. EIPIC CENTRES IN SINGAPORE

VWO	Centre/Programme	Location(s)	Disability
Asian's Women Welfare Association (AWWA)	Early Years Centre	Hougang	All
Autism Association (Singapore)	Eden Children's Centre	Clementi, Simei	Autism
Autism Resource Centre (ARC)	WeCAN Early Intervention Programme	Ang Mo kio	Autism
Canossian School	EIPIC	Circuit Road	Hearing Impairment
Cerebral Palsy Alliance Singapore (CPAS)	EIPIC	Pasir Ris	Autism, Physical, Intellectual, Multiple, GDD
Fei Yue Community Services	Fei Yue EIPIC centre	Jurong East	All
Metta Welfare Association	Metta	Simei, Punggol	Autism, Intellectual, GDD
Rainbow Centre	Rainbow Centre Early Intervention Programme	Yishun Park, Margaret Drive	All except sensory
SPD	Building bridges EIPIC centre	Tiong Bahru, Jurong East	All
Thye Hwa Kuan (THK) Moral Charities	THK EIPIC centre	Woodlands, Choa Chu Kang, Ang Mo Kio, Tampines	All

GDD: Global developmental delay

Adapted from SG Enable EIPIC service matrix.

Proper seating with appropriate relief for deformities allows the child to sit upright and view the environment. General goals include normalisation of tone, symmetric positioning, and improved trunk alignment. Car seating that is safe from both a postural and a crash safety perspective gives secure travel capacity to the child and family.

Oromotor dysfunction may lead to sialorrhoea, silent aspiration and poor intake of nutrition, resulting in poor growth and impact on the social health and general well-being of the child. Thus, most of these children need a full swallowing assessment. Some may only be allowed limited oral feeding or even require gastrostomy tube feeding. They will also benefit from regular review by a dietician for optimisation of nutrition.

B. Sensory

Early-onset sensory impairment such as hearing and visual loss can have a profound impact on a child's development. Specialised skills and adaptive aids enable a child to compensate for such deficiency.

A child with a disability needs to communicate in order to interact with his environment. Communication need not be vocal in nature to be effective. A shared understanding between two individuals may be possible with gestures, sign language or even a simple movement of eye gaze. Augmentative and alternative communication (AAC) may be employed to further enhance understanding and expression.

If the child is unable to express himself, especially if he is non-ambulant, caregivers and health care providers should pay attention to pain that may be caused by various reasons such as muscle spasm, mal-aligned joints, undetected dental caries, skin breakdown, constipation and gastric reflux.

C. Neurological

In cases like cerebral palsy, seizures and movement disorder need to be controlled. In cases of spina bifida with hydrocephalus, ventriculoperitoneal shunt-related complications are not

uncommon. For advanced cases of progressive neuromuscular disease such as spinal muscular atrophy and Duchenne muscular dystrophy, there may be a need for home mechanical ventilatory support.

D. Cognitive

In cases of learning and attention disability, coping strategies are provided to the child as well as the family. Referral to THE neuropsychologist should be made for formal assessment and specific intervention.

E. Psychosocial

Different psychosocial issues may arise at different stages in life in a child with a disability. At the time of diagnosis, the parents are often emotionally devastated and cycle through phases of denial, anger, sadness and active coping. As the disease progresses, levels of function and demands on the family may change. Thus, appropriate psychosocial assistance such as support group and respite care should be made available to the child and family at all times. As the child transitions into adolescence and adulthood, attention should be given to the child's emotional growth and psychological well-being. Opportunities should also be given to discuss about end of life care with both the child and the family.

Encourage participation in patient and family meaningful activities

Like education, nutrition and motor functioning, participation in meaningful activities is an important aspect of development and health of the child. It allows children to express themselves, and develop confidence and competence through experimentation and exploration. It also provides the opportunity to understand and assimilate societal rules, develop social skills and form meaningful relationships.^{7,8,9,10} The first step to encouraging participation is to always ask about the child's and the family's

preferences. These preferences can be influenced by the child's motivation, the family's expectations as well as family cohesion and coping. The activity may be as simple as having meals together as a family. If this is identified to be meaningful and important to the child and the family, then it is essential to make sure that the child has proper seating to make this activity possible.

Beyond the family factors, other factors that impact on participation include the school setting, the beliefs and actions of peers, the attitudes of the public, the availability of social support programmes and the accessibility of transportation and built environments.¹¹ For instance, a child with Duchenne muscular dystrophy will be able to go to school independently if he has a motorised wheelchair with accessibility in the school environment such as ramps and elevators.

CONCLUSION

In looking after a child with a disability, the primary health care provider should view the child as an important and valued member of a family. He should have effective communication with the family as well as other members of the health care team. Routine well child care should not be overlooked, with careful attention paid to monitoring of growth parameters, screening of hearing and vision, and maintenance of appropriate immunisations. Feeding issues should also be looked into in order to minimise risk of aspiration and faltering growth. The primary health care provider should also make sure that every child is given an opportunity to early intervention and education. Consideration should also be given to the management of co-existing conditions such as pain secondary to an ill-fitting orthotic, unnoticed dental caries or severe constipation that may interfere with their daily lives and engagement in meaningful activities.

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LEARNING POINTS

- **The International Classification of Functioning, Disability and Health (ICF) offers a framework for a holistic, multi-disciplinary and goal-oriented team approach in rehabilitation of infants and children with disabilities.**
 - **Family centred care is the fundamental key in the management of infants and children with disabilities.**
 - **The primary health care provider should pay careful attention to monitoring of growth parameters, nutrition and immunisations of infants and children with disabilities.**
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