Rehabilitation
Institutional Care & Community Care

Content
- Definition of rehabilitation
- History and development of rehabilitative service in HK
- Paediatric rehabilitation
- Hospital care VS community care
- Case sharing

Evolution of Rehabilitation Concept (HK)
- Early Stage (before 1950)
  - Piece meal
  - By charitable bodies and voluntary agencies
  - Temporary assistance
- 1950 - 1970
  - More systematic
  - Government support
  - Provide training etc.

Development of Rehabilitation Policy
- Policy Formulation & Co-ordination of Services
  - The Labour & Welfare Bureau
  - Review & co-ordinate with Government Dept. & NGO
  - Strategic direction & priorities for rehabilitation policies and services

Rehabilitation
Enable people with disabilities to reach and maintain optimal physical, sensory, intellectual, psychological and/or social function

WHO
**Policy Objective for Rehabilitation (HK)**

- Preventive Measure
- Help persons with disabilities develop their physical, mental, and social capabilities to the fullest extent which their disability permits
- Design on Barrier Free Access

To ensure their overall well being, inclusion in the community and achieve the common mission “equal opportunities and full participation”

**Rehabilitation Services (HK)**

- Prevention & Early Identification
- Special Education & Training
- Vocational Rehabilitation
- Medical Rehabilitation
- Social Rehabilitation Services
  - Housing, Residential Care
  - Transport, Access Facilities
  - Welfare Allowance
  - Sports & Recreation

**Goal of Rehabilitation**

- Improve the functional ability
- Promote independence
- Promote quality of life
- Back to the community

**Study on Persons with Disabilities & Chronic Illness of the Total Population of Hong Kong (6,600,000)**

<table>
<thead>
<tr>
<th>Disability</th>
<th>Number</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Physical Handicap</td>
<td>103,000</td>
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<tr>
<td>Visual Impairment</td>
<td>73,000</td>
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<td>Hearing Impairment</td>
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<td>Mental Illness</td>
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<td>Autism</td>
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<tr>
<td>Mental Handicap</td>
<td>74,000</td>
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**Persons with Chronic Illness**: 682,700 (13%)

- Household survey – Conducted on a voluntary reporting basis – Estimates of persons with mental illness, mental handicap, autism spectrum and intellectual

**Growth and Development**

Normal development is a function of the maturity of the nervous system and experience.

What about Children?
Problem of Interference of Normal Maturation of the Brain by the Lesion

- Retardation or arrest of normal development
- Numerous aspects of disabilities

World Health Organization (ICF)

International Classification of Functioning, Disability, and Health

A model to guide clinical thinking, practice for children with developmental disabilities

International Classification of Functioning, Disability & Health (ICF)

Health Condition

Cerebral Palsy

Activities

Mobility

Self-care

Object manipulation

Written communication

Participation

Involvement in home life, education, community event and social relationship

Impairment

Skeletal alignment

Range of motion

Muscle performance

Fitness

Environmental Factors

Accessibility

Accommodation

Physical support

Emotional support

Personal Factors

Age

Gender

Interest

Personality

Self-Efficacy

Assessment of a Child with Disability

Knowledge of normal growth pattern functional milestones and potential deviation is important to the comprehensive management of children with developmental or acquired disabilities

Milestone in Child Development

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Milestone in Child Development

3 months
- Supports on forearms in prone
- Hold head up steadily
- Hands open rest
- Coos
- Anticipates feeding
- Follows in circular fashion

6 months
- Sits well unsupported
- Reaches with either hand: Transfers cubes
- Babble
- Sense of belonging to a central person

2 years
- Walks up and down stairs alone
- Turns one page: Imitates vertical stroke
- Uses 2 word sentence
- Feeds doll with bottle
- Begins toilet training

3 years
- Pedals tricycle
- Up and stairs alternate feet
- Copies circle
- Uses 3 word sentence. Minimum 250 words
- Knows age, sex
- Group play

4 years
- Hops, skips
- Catches ball with hands
- Know colours, ask question
- Button clothes
- Play well in group

5 years
- Jumps over low obstacles
- Draws man with all body parts
- Fluent speech
- Plays competitive games

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**Milestone in Child Development**

7 years

- Continue refinement of skills
- Eats with fork and spoon
- Self grooming
- Fact Vs fiction

**Milestone in Child Development**

Adolescence

- Skills refined
- Abstract thoughts/ hypothesis
- Stage of identity Vs role confusion
- "Group" identity

**Paediatric Rehabilitation**

- Congenital Disabilities (Congenital Origin)
- Acquired Disabilities (Trauma / Disease)

**Common Congenital Disabilities**

- Cerebral palsy
- Mental retardation
- Spinal bifida
- Joint disease
- Skeletal disorder
- Neuromuscular disease
- Neurometabolic disease

**Common Acquired Disabilities**

- Head Injury
- Spinal cord injury
- Brain injury/ Surgical interventions
- Burns
- Amputations

**Functional Disabilities**

- Visual problem
  - Blindness
  - Low vision

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**Functional Disabilities**
- Hearing problem
- Feeding problem
- Learning difficulties
- Attention deficit
- Autistic

**Care & Management for Children with Disabilities**

**Rehabilitation Vs Habilitation**

**Rehabilitation**
- Acquired physical disability
- Loss of previously mastered skills
- Restoration of lost function

**Habilitation**
- Congenital anomalies, neuro-developmental delay...
- Do not have normal abilities early in life
- Acquisition of new function

**Rehabilitation Vs Habilitation**

**Rehabilitation**
- Relearn of previous skills. In essence, management of change
- Require adjustment to alter functional ability and life style

**Habilitation**
- Develop new skills to enable to function within given environment
- Develop new skills to achieve maximum potential

**Uniqueness of Paediatric Habilitation/Rehabilitation**

**Concept of Plasticity of Children’s Brains**
- Early intervention ➔ improve outcome
- Periodical re-evaluation, regular interval assessment ➔ update the status of children
- Planning and intervention re-adjustment ➔ changing needs

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**Promotion of Family-Centred Care**
- Child ➔ integral part of a family
- Home ➔ central focus of a child’s world
- Co-ordination of care, with family as part of healthcare team
- Assist family share an important role in shaping the child’s future

**Focus on Developmentally and Functional Abilities Support Care**
- Assessing children’s developmental profile (current development in physical, cognitive, social and emotion)
- Assessing children’s functional abilities (understanding what a child actually does)
- Planning creative strategies --- address on unique developmental needs
- Predict and planning short term/long term realistic goals

**Paediatric Rehabilitation Services in Hong Kong**

**Preventive Measure**
- Ante-natal Care (early detection of abnormality, genetic study)
- Child Health & Development Surveillance
- Child Assessment Centre

**Child Assessment Centre**
- Referral request from other Agency
- Assessment Clinic
  - Investigation
  - Further Assessment by Team Member
  - School Placement
  - Treatment/Training program
  - Case Conference / pre-admission Conference
- No
- Ready for discharge
- Yes
- Follow-up arrangement

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Rehabilitation Institutional Care & Community Care

Pre-school Services
- Social Welfare Department - Central Referral System
- Integrated Child Care Centre (ICCC)
- Special Child Care Centre (SCCC)
- Early Educational Training Centre (EETC)

Primary & Secondary Education
- Education Department Bureau - Special Education Section
  - Special School
  - Remedial Class
  - Resource Support

Hospital / Institutional Care

Community Care

Pulmonary Rehabilitation Program
Regular periodical monitoring of pulmonary function for patients with neuro-muscular disease
- Sleep study
- SpO2 monitoring, LFT, Blood Gas
- Arrangement of equipments if ventilator support is initiated as well as patient / parent training
- Ventilator (BiPAP / CPAP) titration
- Support for chest maintenance

Intermediate Care / Step Down Care
with Rehabilitation Program
- Manage patients with multiple disabilities / high dependency level / complex medical & rehabilitative needs
- Family centered approach
  Facilitate parent as equal partners in the caring and managing of children

Rehabilitation Team

Framework of Rehabilitation Nursing

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Common Disability – Feeding Problem

Hindrance to Feeding
- Inability to sit independently in an upright position
  - Poor head control
  - Poor trunk control
  - Involuntary movements

Hindrance to Feeding
- An exaggeration of normal feeding skill
  - Tonic bite reflex
  - Tongue retraction
  - Hyperactive gag reflex

Hindrance to Feeding
- Poor coordination of the Jaw, Lip, and Tongue
  - Poor lip closure
  - Poorly controlled tongue movement
  - Poor chewing pattern

Hindrance to Feeding
- A delay in the normal progression of feeding skills
  - Inability to grasp food or to finger feed
  - Difficulty in cup drinking
  - Difficulty using a spoon

Oral-Motor Rehabilitation Program
- Video Fluoroscopy Swallowing Study (VFSS)
- 24 Hours PH Study

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**Oral-Motor Rehabilitation Program**
- Feeding training
  - Monitor of growth & nutritional status
  - Monitor signs of aspiration
  - Ensure safe feeding regime
  - Adjust food consistency
  - Ryle's tube feeding / Gastrostomy care

**Common Disability - Epilepsy**

**Epilepsy Rehabilitation Program**
- VEEG monitoring
- Seizure monitoring & Drug titration
- Post epilepsy surgery rehabilitation
- Parent education
  - Emergency management
  - Ketogenic diet
  - Drug regime

**Medical Conditions for Tracheostomy/Long term ventilator Assisted**
- Upper airway abnormalities
- Craniofacial syndrome
- Mucopolysaccharidosis
- Down syndrome
- Skeletal dysplasia e.g achondroplasia
- Spinal muscular atrophy
- Congenital myopathy
- Congenital hypoplastic lung

A youth, stayed few years in Intensive Care Unit. Something can be done....

Children born with Muscle disease 
- Dependent on wheel chair for mobility
- Need machine to assist breathing
- Family has difficulty looking after

A HDU case - a Child hook on Ventilator since 3 months old...
In-patient Step Down Care for Assisted Long Term Ventilation

- ICU, HDU
- Rehab Ward - Ventilator Care Program
- Family oriented
- Patient / care taker empower

Home

Society

School

Can They Allow Home Care?

Hindrance to Discharge/Community Integration

- Incompetent parents
- Problem in recruitment of trained carers

Hindrance to Discharge/Community Integration

- Parent’s acceptance of shoulder the power shifting
- Social implication
  - Offended by reactions faced
  - Living isolated
- Environmental factors

Pave the Road Home

- Most important consideration
  - When to start
  - How to start

Confronting parental responsibility

- Impact on family relationship
  - Need devoted extraordinary care and attention to child’s need
  - Sibling’s resentment towards of being neglected
- Single parents
- Family stress
  - Living with daily threat of death
  - Worry of child’s transition to adult life

Need devoted extraordinary care and attention to child’s need

Sibling’s resentment towards of being neglected

Living isolated

Worry of child’s transition to adult life
When to Start
- Medical condition stable
- Psychological preparation for parents
- Allow times for parents to digest the rehabilitation plan

How to Start
- Identification of carers
- Shared decision making
- Parental empowerment
- Open communication

Pave the Road Home
- Pre-transfer screening
  - Build up rapport
  - Assess complexity patient’s status
  - Match patient’s need with available resources
  - Understand and communicate both expectations
    - Resource & manpower in care is explained
    - Treatment available at different stage is made known
    - Stages of pulmonary decline should be explained
    - Formulate rehabilitation plan

Pave the Road Home
- Pre-discharge planning
  - Initiate the rehabilitation and educational program for carers with set time frame
  - Periodical progress meeting with parent / carer
  - Home visit & home leave plan

Environmental Adaptation & Home Training
- Identify the environmental barriers of living environment
- Integrate child into society & discharge home safely

Pave the Road Home
- A Case Study
  SMA Child discharged home with invasive ventilator support
Rehabilitation Program and Discharge Plan for SMA Child with Invasive Ventilation

Identification of Care Taker
- Mother
- Maid
- Father

Communication & Collaboration
- Formulate the master training program is very important and with the time frame
- Periodical case conference is needed so that the team members and the parents had mutual agreement on the discharge plan

Speech therapist
- Use of speaking valve
- Communication
- Oro-motor function

Physiotherapist
- Chest maintenance
- Suction techniques
- Care of suction machine
- Limb exercise

Occupational therapist
- Transfer
- Wheelchair setting with ventilator & external battery
- Home modification

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Medical social worker
- Funding application
- Financial assessment
- Re-housing
- Solve the family conflict

Clinical psychologist
- Psychological preparation
- Solve some family conflict

Nurse
- Gastrostomy care
- Tracheostomy care
- Ventilator care
- Use of manual resuscitator
- Prepare patient for outing / home leave
- Solve family’s conflict

The Go Bag
- For emergency
  * Spare same size & down size tracheostomy tubes
  * Tracheal dilator
  * Suction tubes
  * Resuscitator

Outing Strategy
- Parent’s education program completed & passed
- Patient outing with parents
  * with nurse escort for few times
  * without nurse
- Patient outing
  * within hospital compound
  * outside hospital area

Step Down Approach
- Parent’s skills and confidence build up in escorting the outing
- Try day home leave
- Home visit by team members
- Home modification will be proceed
- Plan for overnight home leave

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Preparation for Overnight Home Leave
- Concrete daily schedule need to offer to care taker
- Back up machine if the child had no unplug time
- Letter to the A&E department in case of crisis

Facilitate Discharge Plan
- Arrange mother to stay overnight in mother and child room to facilitate overnight home leave
- Assess mother’s skill
- Solve problems arising during the stay

Work on Equipment List
- Essential equipment list
- For funding application
- Or rent to own scheme

Other Preparation
- Estimate monthly consumption
- Purchasing list of the essential consumable items

Other Back Up Services
- CNS service
  * Monitor of progress
  * Psychological support
- 24 hours hot line enquiry from ward
- Respite care

Discharged Home

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Hospital → Community - Home, Social Activity, Leisure, School

Community Support Networking in HK
- Education Department Bureau
- Social Welfare Department
- Community nursing
- Housing
- Transport
- Emergency attention
- Employment

Our Wishes
- Children with chronic disabilities be able to grow up in a supportive & loving environment
- They are able to grasp their strength and abilities
- Contributing to the society and be part of the community

THANK YOU