Challenges for Healthcare for Persons with Intellectual Disabilities in Low Income Areas

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What is Health?

“State of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO)

Health is a valuable resource that enables people to lead individually, socially and economically productive lives, providing them with the freedom to work, learn and engage actively in family and community life.
Inclusive Health Care

• Builds on the primary health care concept “Health for ALL” (Declaration of Alma Ata)

Healthcare should be "……. ….. accessible to individuals and families in the community and at a cost that the community and the country can afford".

Inclusive Health Care

To ensure this

• Health systems must recognise and accommodate the needs of PWD in their policies, planning and service delivery

• Health Care service providers need to have positive attitudes towards disability and appropriate skills to accommodate needs of people with different impairments

• PWD & DPOs/SHGs actively participate in the planning and strengthening of healthcare and rehabilitation services
Determinants of Health and Ability

*Influenced by a range of factors:*

a) **Personal**
   (genetics, individual behaviours and lifestyles, gender)

b) **Social**
   (education, health services, support networks)

c) **Economic**
   (income, occupation, employment conditions)

d) **Environmental**
   (culture, community characteristics including physical environment)

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Public Health Determinants

Dalhgren and Whitehead, 1991
Determinants of Disability

- Determinants of disability are also rooted in environment, socioeconomic organization, social rules producing inequality and cultural factors

“For the differently abled child from a poor family, disability is but one aspect”
Health Care Needs Of Individuals With Disabilities

1. Broad Public Health measures that benefit the entire population
   E.g. Potable water
        Sanitation
        Immunization
        Nutrition
   PWD experience most of the health conditions experienced by persons without disabilities

2. Access to Health Services and Health Education
   (Contd…)

3. Specific health care needs:
   • Thinner margin of health & predisposition to infections. Impairments and functional limitations render them more vulnerable to certain health problems
   • Health maintenance and preventive care
   • Earlier onset of chronic health conditions
   • Secondary functional losses
   (Contd….)

(Contd….)
• 3. Specific health care needs (contd.):

• Need to learn with the help of Mobility/ Assistive Devices and Adaptive Equipment

• More complicated and prolonged treatment for a given health problem

• Sustained pharmacologic support for some conditions (epilepsy, long-term mental illness)

• Long term services (personal assistance & ongoing medical supervision)

Ensuring PWD achieve good levels of health measures

• **Recognizing** that they need health services for general healthcare needs like the rest of the population, including different needs in different phase of life

• **Understanding** that some may also have health problems related to their impairments, on occasional or regular basis, for limited or lifelong periods
Early Identification of Intellectual Difficulty (Survey, Pediatric Developmental Clinics, Pre-Schools and Schools)

Identification of Existing Services & Facilities for Need Based Educational Programmes (Special and Mainstream)

Habilitation and Rehabilitation (Community & Institutions) With a Lifespan Approach

Inclusion, Participation & Empowerment
Integrate OT, ST into ECCE for all with delayed development

Learning Support in Community Schools, CBR Partnerships with Education

Accessibility, Training Support, SHG, Social Networks

**CBR and Elements of Health**

- Health Promotion including SDH
- Prevention (including SDH)
- Medical Care (General)
- Specific Health Care Services including early intervention
- Assistive Technology, Reasonable Accommodation
- Habilitation/Rehabilitation
Health Promotion (WHO, 2005)

- Process of enabling people to increase control over their health and its determinants, and thereby improve their health

When public awareness of social determinants of health is raised, people will find ways to apply the knowledge in a range of activities

It is also the essence of democracy

Health Promotion for PWD

- General Health Promotion
- Specific Health Promotion for Individual
- Activities to deal with barriers to health
- Health Promotion for family members
- Health Promotion Action
Health Promotion for PWD

**Activities** – Depend on local issues and priorities; Also influenced by policy framework and public awareness

**Strategies** -
1. Build healthy public policy (legislation, regulation)
2. Create supportive environment for health (physical, social)
3. Strengthen communities (adopt community approaches to address health problems)
4. Develop personal skills (Information, health education)
5. Reorient health services (Convergence with education and social justice sectors)

The Challenges

*Greatest challenge for caregivers in CBR Initiatives lies in:*

1. Developing Participation in disadvantaged communities which require
   a) high degree of orientation to developmental issues
   b) striking the right balance with rights, responsibilities and needs – both individual & community’s

2. Making Health Care Inclusive and Accessible to ALL
Multifaceted challenges of children with special needs can be best addressed by

1) Properly trained & sensitive careproviders
2) Involving larger community in the challenging task
3) Responding to challenging needs in a globalizing world
4) Integrating disability-related healthcare into a wider development process
5) Coalitions and collaborative functioning

**Community Coalitions**

**Community Partnerships for Health (CPH)**

- Organisations of individual representatives diverse organisations or groups agreeing to work together in order to achieve a common goal.
- Organisations of diverse interest groups that combine their human & material resources to effect a specific change with members are unable to bring about independently (Synergy).
Bergen Model of Collaborative Function

Gaps

- **Inequity**
  - Rich-Poor
  - Urban-Rural
  - Education-Illiteracy
  - Gender

- **Communication Gap**
  - Between those who need primary care services and the organized health sector
  - Between various stakeholders

- **Lack of Convergence for programmes by different Ministries**
Bridging the Gap

What Facilitates:

• Health systems geared to prevention and limitation of disability
• Human rights protection
• Advocacy and network for support services
• Equipment and technology
• Legal empowerment
• Awareness (IEC)
• Research and training
• Human resource development

Universal Health Care Coverage and Inclusive Health and Rehabilitation Services

• PWD need and use disproportionately more health care services than do those without

• Awareness, organization, to be involved in political processes that shape their healthcare systems

A person with a disability will rarely fare better than the general standard of living of people around him; to improve the quality of life for PWD does not only imply equalizing individual opportunities but also improving the life conditions of the whole family and community providing care
The “CARENIDHI” MODEL FOR COMMUNITY-BASED REHABILITATION
From Evidence to Empowerment—How we do it:

- We study childhood disability in the community
- We involve the community in action to reach out to the children
- We seek to understand the child’s abilities and contextual development
- We help the family and child to enhance activity & participation
- We support the rights of the children with disabilities with a family-centric approach
- We enable the children to develop into young citizens with responsibilities

Research on Childhood Disabilities, developmental disorders & determinants

(Epidemiological studies to identify vulnerable groups and risk-factor associations)
Training care-providers in early intervention and supporting public health activities

(To decrease developmental problems in infancy and Early Childhood)

Health Promotion in the community & Multi-disciplinary Action for Prevention

(Mobilize local health care personnel and social workers for rehabilitation and special care needs)
Integration of Disability-related initiatives into wider issues of community development

(Public awareness campaign, capacity building for social capital and Policy)

THANK YOU