

Services for the Child with a Disability (CWD)

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Foreword

Disability need not be an obstacle to success. I have had motor neurone disease for practically all my adult life. Yet it has not prevented me from having a prominent career in astrophysics and a happy family life.

Reading the *World report on disability*, I find much of relevance to my own experience. I have benefitted from access to first class medical care. I rely on a team of personal assistants who make it possible for me to live and work in comfort and dignity. My house and my workplace have been made accessible for me. Computer experts have supported me with an assisted communication system and a speech synthesizer which allow me to compose lectures and papers, and to communicate with different audiences.

Professor Stephen W Hawking

Source :World report on disability – WHO , World Bank 2011

Introduction

- PNG's national disability policy emphasizes the protection of human rights, inclusiveness, barrier free services and partnerships for an estimated 1 million people with disabilities (PWD) living in PNG.
- ~5% of children in PNG have a disability (CWD) although there is little data on exact numbers
- ~2% of PWD and CWD are able to access support services such as community based rehabilitation and special education resource centers.
- “Disability is a development issue, because of its bidirectional link to poverty: disability may increase the risk of poverty, and poverty may increase the risk of disability” (WHO World Report on Disability 2011)

Guiding policies



WHO Global Disability plan 2014 -2021

Action plan with 3 main objectives;

- (1) to remove barriers and improve access to health services and programs;
- (2) to strengthen and extend rehabilitation, habilitation, assistive technology, assistance and support services, and community-based rehabilitation; and
- (3) to strengthen collection of relevant and internationally comparable data on disability and support research on disability and related services

The design and implementation of the action plan are based on and guided by the following approaches:

- a human rights-based approach, including empowerment of persons with disabilities
- a life-course approach, including the continuum of care
- universal health coverage
- a culturally-appropriate person-centred approach
- multisectoral/community-based rehabilitation
- universal design

Presentation of disabilities

There are a number of ways in which disabilities can become apparent:

- Antenatally or at birth if physical anomalies are present.
- In the first year of life for motor or severe learning disabilities.
- In the second or third year of life for moderate learning disabilities, language disorder or autism.
- Following a cranial insult.

Causes of disability in childhood

- May be Developmental OR Acquired
- Causative factors are heterogeneous and complex and their contribution in producing disability may differ in different populations
- a substantial % of all disability of unknown cause

Examples of developmental disability

- ADHD
- Autism spectrum disorder
- Cerebral palsy
- Hearing loss
- Intellectual disability
- Vision impairment
- Other developmental delays

Causes of disability in childhood

- i. **PRENATAL** - : genetic factors, genetic diseases, developmental malformation, maternal age, maternal diseases, drugs/medicines/chemicals/radiation, consanguinity, ethnic group
- ii. **PERINATAL** –: low birth weight/prematurity, obstetric complications, trauma during labour, asphyxia, intracranial hemorrhage
- iii. **POSTNATAL** - : infections (polio, TB, meningitis, encephalitis, endemic diseases (goitre/cretinism), accidents, malnutrition, poisoning, tumors, environmental factors, psychosocial problems

Range of disabilities

1. PHYSICAL

- many physical disabilities that can affect children, such as delayed walking, deafness or visual impairment
- Most common is Cerebral Palsy (CP) ,an umbrella term for a broad group of non-progressive motor impairment conditions secondary to lesions or anomalies of the brain arising in the early stages of development
- Use of adaptive equipment such as powered mobility, augmentive communication systems eg sign language and picture boards, can have impressive and widespread impacts on social, language and play skills as well as encouraging independent movement
- other conditions eg. Asthma, diabetes,that may not be traditionally seen as disabilities but are chronic in nature and therefore can have an impact on the child's development in more subtle ways (eg through days lost at school, inability to partake fully in physical activities, need to take medication regularly).

2. LEARNING DISABILITIES

- may be caused by genetic factors, infection prior to birth, brain injury at birth, brain infection, brain damage after birth or due to an unknown reason, significant list of associated conditions, such as Down's syndrome.
- The effects may be far-reaching, with speech and communication problems which can result in (or be associated with) behavioural problems.
- Associated physical problems are common.

Effects on the family

- Social isolation:
- Financial implications
- Implications for siblings

Prevention of disability

- Prevention of birth defects eg. Pre - conceptual folic acid to prevent NTDs
- Vaccination
- Supervised deliveries to reduce BA, birth related injuries
- Developmental screening
- Nutrition – Improving rates of exclusive breast feeding, reducing malnutrition, reducing anaemia and micronutrient deficiencies
- Many causes are not preventable and so the child will have to live with the effects of this disability

Management of CWD

- ❑ CWD may be identified at a health facility or in the community
- ❑ May be referred/brought to a rehabilitation centre eg. Cheshire home, Callan services, PT, paediatric clinic or remain at home with family
- ❑ Most services for PWD and CWD nationwide are provided by CBOs, NGOs
- ❑ Data on the frequency of CWD, the types of disability , or the services required by CWD is lacking /unknown in government agencies such as health and community development.
- ❑ Each province have their own pathway for CWD and PWD, and the physiotherapy department in hospitals may be the focal point for those with a physical disability and from where rehabilitation services coordinated
- ❑ Other areas where CWD may be seen -Paediatric clinics, ENT, Ophthalmology ,Surgical clinics/wards.
- ❑ Limited/unavailable services– speech therapy, occupational therapy, hearing and vision screening, special education services

Organizations that work with people with disability in PNG

- NDOH Physiotherapy and NOPs
- VSO
- Callan Services –
 - Inclusive Education Resource Centres (IERC)
 - Ear and hearing services
 - Optical Services
 - Community based rehabilitation programs
- Vision – Mt Sinai, Fred Hollows Foundation,
- Cheshire home

Services for children with disabilities can be improved by:

- ❑ Improve school participation for children with disabilities
- ❑ Birth registration for all children, including babies born with disabilities
- ❑ Strengthen referral pathways for children with disabilities from all provincial peripheral health facilities to enable registration
- ❑ *Improve database on CWD through registration – Com DEV or Physiotherapy Department or other focal point in hospitals.*
- ❑ Strengthening or establishment of developmental screening programs for children at early education centers and in major hospitals.
- ❑ Increasing support to community organizations who work with disabled children.
- ❑ Strengthening multi-disciplinary health services for children with disabilities
- ❑ Training of nurses and paediatricians in supporting children with disabilities and their families

Key messages for Provincial and District Health Staff

Provinces and communities should have programs to support children and adults who have disabilities, to offer them every opportunity to thrive and reach their full potential, and to be contributors to the community.

Services for children with disabilities can be improved by:

- Encourage school participation for children with disabilities.
- Increasing support to community organizations who work with disabled children and adolescents.
- Strengthen multi-disciplinary health services for children with disabilities.
- Start a parent-support group for caregivers of children with disabilities, this can really support parents who otherwise feel isolated.
- Train nurses and paediatricians in supporting children with disabilities and their families.

References

1. World report on disability – WHO , World Bank 2011
2. National Policy on Disability PNG, 2015 – 2025, Dept of Community Development and Religion, GoPNG
3. PNG National Health Plan
4. Papua New Guinea Child and Adolescent Health Policy and Plan , 3rd edition
5. National Guidelines on the Provision of Assistive Technology in Papua New Guinea Zero Draft – April 2016
6. National Early Childhood Care and Development policy