

BASIC FACTS & SERVICES FOR CHILDREN WITH AUTISM IN BANGLADESH

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Introduction

Autism spectrum Disorder (ASD):

- **A child psychiatric disorder within 'Developmental' category**
- **Evolved from rare to frequent condition with tremendous impact in provision of services and in the life of those affected by them & their families**
- **Based on diagnostic triad of Autism and other PDD both in ICD & DSM Classification of Psychiatric disorder**

Introduction

Concepts of ASD

TWO concepts:

1. **Homogeneity** : Kanner's description of classical autism & conditions similar to it with common aetiology
2. **Heterogeneity**: diagnostic & aetiological variants within a unique characterization. It include a number of medical disorders with such presentation e.g. VI, HI, TSC, DS

Introduction

Some fact & findings on ASD

- Consistent reports on genetic predisposition
- Early & Regressive autism - no consistent findings
- EEG changes – a mediating pathophysiology
- Inconsistent findings of neuroimaging & thereby inconclusive
- No medical tests for diagnosing
- Relation of autism with MR, Hyperactivity well established but unexplained
- More occurrence of seizure disorder in late childhood & onwards – unanswered
- Tremendous impact and huge involvement of pluralistic professionals & resources
- Earlier the intervention, the better long term prognosis for a more normal ,productive life

Introduction

Children and adolescents in Bangladesh

- **<18Y: roughly 45% of population**
- **Subject to conditions with negative impacts that affect physical and psychological well being**

Introduction

PREVALENCE

Child psychiatric disorder

Global (Review of leading studies)

Any Disorder 10 - 25%

ASD 0.1- 1.9%

Bangladesh (Mullick et al,2005)

Any Disorder 15.2% (10.9-20.8%)

ASD 0.2% (0.1-0.9%)

Introduction

Major Correlates of ASD in Bangladesh (Mullick et al, 2005)

- More among boys
- More in urban area
- Higher Comorbidity - Hyperactivity, MR, Seizure disorder, Emotional disorder, Behavioural (Aggressions, self-injurious)
- Victim of unrecognising- maltreated, more distress, impairment & social disability, stigmatised

Introduction

Magnitude of the Problem

- **Very conservative extrapolation that roughly 1% has ASD**
- **that are severe enough to result in substantial distress or social impairment**
- **thereby warranting a diagnosis, and warranting management too**

Services for Children with ASD

History of Service Development

- 1975 Child Guidance Clinic in DMCH
- 1977 Society for Welfare of the Intellectually Disabled (SWID)
- 1984 Foundation for Developmentally Disabled (BPF)-
for special education and community-based rehabilitation
- 1991 First Child Development Unit began within Dhaka Children Hospital
- 1992 Establishment of Institute of Child & Mother Health
- 1998 First Child Mental Health Clinic in BSMMU (IPGM&R)
- 1998 Child Development Center in Mother & Child Hospital, Chittagong
- 1999 Child Development Center in BSMMU & ICDDR,B
- 2000 National Institute of Mental Health with CMHC
- 2000 Child Development & Neurology Care Center in DMCH

Service Facilities for Children with ASD

- **Tertiary level :**

Assessment, diagnoses, community referral, treatment of comorbidity, periodic follow-up

- **Secondary & Primary level :**

Poor / no efficiency in early detection & and intervention

- **Community Services :**

Screening, Special education, vocational trainings, rehabilitation, hospital referral

Service Facilities for Children with ASD

Tertiary Level of Institutes located at major cities

- **BSM Medical University (BSMMU)**
 - Outdoor-indoor Services in the Dept. of Psychiatry (Child & Adolescent Wing), Paediatrics (Paediatric Neurology Unit & CDC), & ENT (Paediatric Audiology Unit)
- **National Institute of Mental Health(NIMH)**
 - Outdoor-indoor Services (Dept. of Child, Adolescent&Family Psychiatry)
- **Medical College Hospitals**
 - Outdoor-indoor Services in the Dept. of Psychiatry, Paediatrics & Neurology (CDC)

Service Facilities for Children with ASD

Tertiary Level of Institutes located at major cities

- **Dhaka Shishu Hospital**
 - Outdoor-indoor Services (Child Development Neurology Unit) by MDT
- **Institute of Child & Mother Health**
 - Outdoor-indoor Services, CDC with MDT
- **Institute of Child Health & Shishu Sasthya Foundation Hospital**
 - Outdoor-indoor Services, CDC
- **ICDDR,B**
 - Child Development Unit

Service Facilities for Children with ASD

As part of LD Services at Community Level

- **Society for the Welfare of the Intellectually Disabled (SWID)**
 - National Institute for the Intellectually Disabled
 - Organized Developmental Programme
 - 49 Special schools for LD throughout the Country
- **Bangladesh Protibondhi (Developmentally Disabled) Foundation (BPF)**
 - 2 Special Schools for LD
 - Vocational training
 - Distance Training Programme for the outreached children with LD
 - 6 Rehabilitation Programme Centres
- **National Centre for Special Education**
 - Special school , vocational training and residential care at Dhaka
- **National Institute for Mentally Retarded Children**
 - Special school and residential care at Chittagong

Service Facilities for Children with ASD

Services for Autism at Community Level

- **Training & Education for Autistic Children (TEACH)**
- **Society for the Welfare of the Autistic Children (SWAC)**
 - 1 school for 84 autistic children in Dhaka
 - Parental counselling & education
 - Awareness programme
- **Autism Welfare Foundation (AWF)**
 - 1 School for 50 autistic children in Dhaka
 - Distance Training Programme for the outreached children with ASD
- **Beautiful Mind**
 - 1 school in Dhaka
- **School for Gifted Children**
 - 3 schools – 1 in Dhaka, 2 in Rajshahi
- **Other 11 Schools**
 - Almost all in Dhaka, poorly organized, some disappeared

Training Facilities for the Professionals for Children with ASD

- **Psychiatrists -part of Child & Adolescent Psychiatry and Learning Disability Psychiatry in postgraduate curriculum**
- **Paediatrician – small part of Child Development in postgraduate curriculum**
- **Clinical Psychologist- part of Child Psychiatry & Development in curriculum**

Training Facilities for the Professionals for Children with ASD(Cont..)

- **Training for the professionals of MDT (Doctors, Therapist, psychologists) in Dhaka Shishu Hospital**
- **Graduation and Masters Course in Special Education in Teachers Training College (Bangladesh Institute of Special Education)**
- **Undergraduate curriculum ?**

Existing Services for ASD

- **Specialized services restricted to tertiary hospitals**
- **Community based services mainly with LD services**
- **Though praiseworthy, except a few, community based services lack both quantity and quality, confined within large cities, costly**
- **Poorly organized schools with inadequate staff**
- **lack of trained service providers**
- **Nonexistence/partly organized MDT**
- **Weak coordination and communication between service agencies**

Existing Services for ASD

- Little or no access for the vast affected children
- Massive gap exists between need and service provision
- Severe shortage of resources, professionals
- Little prospects of meeting this need in near or far future by developing systematic and planned professional services despite of willingness & ability to accept modernity and scientifically based service model

Developing Services for Children with ASD: Basic Considerations

- **Different from Western model**
- **Based on available resources**
- **Part and parcel of NHS & NCHS**
- **Integrated part of NMHS**
- **Provided through School Health Service**
- **MDT will be different in composition and competency**
- **Collaborative action between health, social & educational agencies**
- **Active involvement of private sectors**

Key Strengths of Bangladesh

- **Strong family & neighborhood support in child care inherent in the culture**
- **Excellent infrastructure of NHS**
- **Adequate “potential” manpower**
- **Growing number of non-government agencies for child care**
- **Increased medical education**
- **Growing awareness about Autism-
parents with autism, professionals,
agencies, concerned media**

Strategic Points for Feasible Services for Children with ASD

- **Adopting a policy to develop resource-based non-specialist services**
- **Adequate provision of training of the trainers for offering training and supervision**
- **Involving “potential” manpower- parents, teachers, child health working staff, GPs, social workers, counselors ,volunteers**
- **Offering short training on Autism to them**
- **Offering coordinated services through health, education, social agencies**
- **Nongovernmental approach with community participation along with Governmental initiatives and support**

Role of BACAMH : Few Suggestions

- **Establishing dialogues & networking**
local / regional / International
organizations
- **Coordinated initiatives**
in resources and need based training
- **Assistances and partnership**
in exchange programs, mutual
assistance

Services for Autism & LD in Bangladesh

CONCLUSION

- Autism is still a mysterious disorder but research is going on with positive hope
- Vast gap between service need and service provisions
- Urgent need to develop resource-based feasible service model
- Achievement possible through trained and supervised non-specialist professionals
- Potential collaboration and networking among regional & international community
- Critical role of Agencies-establishing dialogue, assistance and partnership



Thank you