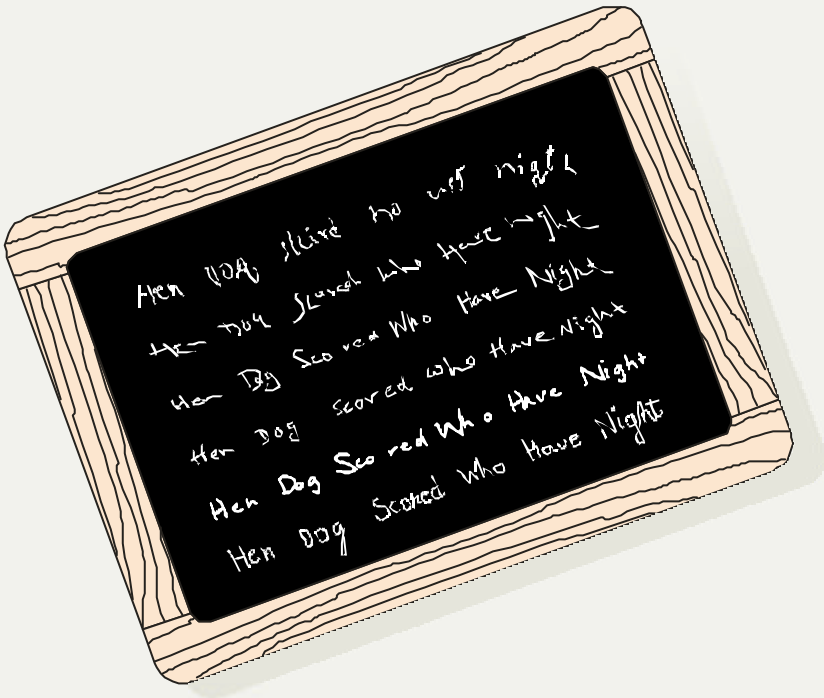
From knowledge
to action

World Health Organization
Regional Officefor South-EastAsia

Mental Retardation



From knowledge to action

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Mental Retardation:
From knowledge to action

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Message from theRegionalDirector

Populations ofMemberCountriesofthe WorldHealthOrganization's South-East Asia Region have suffered for agesfrom many communicablediseases.Whilesomeofthesehavebeensuccessfully controlled,otherscontinueasseriouspublichealthproblems.However, recently, it has become increasinglyclear thatnoncommunicable diseases,includingmentalandneurologicaldisorders,areimportant causesofsufferinganddeathintheRegion.Anestimated400million peopleworldwidesufferfrommentalandneurologicaldisordersorfrom psychosocialproblemssuchasthoserelatedtoalcoholanddrugabuse. OurRegionaccountsforasubstantialproportionofsuchpeople. Thus, theRegionfacesthedoubleburdenofdiseases-bothcommunicable andnoncommunicable.Moreover, with thepopulationincreasingin numberand age, MemberCountrieswillbeburdenedwithan ever-growingnumberofpatientswithmentalandneurologicaldisorders.

AsDr GroHarlemBrundtland,theDirector-GeneraloftheWorldHealth Organization says, "Manyofthem suffer silently, and beyond the sufferingandbeyondtheabsenceofcarelietheirsofstigma, shame,exclusionand,more oftenthanwecaretoknow,death".

While stigmaand discriminationcontinuetobethebiggestobstacles facing mentallyillpeopletoday,inexpensivedrugs arenotreaching many people with mental and neurological illnesses. Although successfulmethodsofinvolvingthefamilyandthecommunitytohelpin recoveryandreducesufferingandaccompanyingdisabilitieshavebeen identified,theseareyettobeusedextensively.Thus,manypopulation groupsstillremaindeprivedofthebenefitsofadvancementinmedical sciences.DrBrundtlandhas said,"Byaccidentordesign,weareall responsibleforthissituationtoday."

TheWorldHealthOrganizationrecentlydevelopedanewglobalpolicy andstrategyforworkintheareaofmentalhealth. Launchedbythe Director-GeneralinBeijingin November 1999, thepolicyemphasizes threepriorityareasofwork:(1)Advocacy toraisethe profileofmental healthandfightdiscrimination;(2)Policytointegratementalhealthinto thegeneral health sector,and(3)Effectiveinterventionsfortreatment andpreventionandtheirdissemination.TheSouth-EastAsiaRegional OfficeoftheWorldHealthOrganizationiscommitted topromotingthis policy.

Mentalhealthcare,unlikemanyotherareasofhealth,doesnotgenerally demandcostlytechnology.Rather,itrequiresthesensitivedeployment ofpersonnelwho have been properlytrainedinthe use ofrelatively inexpensive drugsandpsychologicalsupport skills onanoutpatient basis. What isneeded, aboveall,isforallconcernedtoworkclosely togethertoaddressthemulti-facetedchallengesofmentalhealth.

DrUtonMuchtarRafei
RegionalDirector
WorldHealthOrganization
RegionalOfficeforSouth-EastAsia

Preface

Whenachildwithmentalretardationisborn,theinitialreactioninmost familiesisthatof"gloomanddoom".Sometimesthereisanattempttto determine"whyme?"orblamesomeoneorsomethingforthetragedyin thefamily.InpoorersegmentsofthepopulationofSEARMember Countries,havingachildwithmentalretardationisadoubletragedy;not onlyisthechildunabletocontributetothefamily'sresources,instead he/sheneedsadditionalcaringwhichdrainsthefamily'sresources.Thus, havingachildwithmentalretardationinthefamilyaffectsnotonlythe individualwhohasthis problem,butalsotheirfamiliesandthesocietyas awhole.

Severaladvances in the scientificandsocial understanding of this conditionhaveopenedupavarietyofavenuesandopportunitiesto reduce the impactofthisproblemandlimittheextentofdisability. Strategies f or primary prevention with such simple remedies as adequateintakeofiodinebypregnantmothersarenowavailable.

Evenwiththeirlimited resources, much can beachievedinSEAR MemberCountriesthroughcombinedandcoordinatedactionbythe families,governmentsandnongovernmentalorganizations.Nowisthe t imetotakeupthechallengeandtakeactiontoproducemeaningful results.

Thisdocument,preparedbyapanelofexpertsfromtheRegion,provides valuableinformationonthecurrentstateofknowledgeaboutmental retardation. More importantly,it alsodescribeswaysandmeansby whichbettercarecanbeprovidedto"Heaven'sveryspecialchild"bytheir familiesandothers.

DrVijayChandra
RegionalAdviser,Health&Behaviour
WorldHealthOrganization
RegionalOfficeforSouth-EastAsia

INTRODUCTION

When we see people around us, we observe that some lack normal physical abilities. For example, there are people who are unable to see, hear or speak and others who are unable to move around. These people are commonly known as physically disabled. Similarly, there are people who have poor and insufficient development of mental functions, including control over their body movements, their intelligence, social interaction and language, from birth or early childhood. This condition is called mental retardation.

Recently, there has been increasing awareness that the term "mental retardation" has a derogatory connotation. Thus, the term "mentally challenged" is being used. However, since the term "mental retardation" is well known to the common man, families with patients and policy-makers, this term will continue to be used in this monograph.

At the global level, the last 100 years have seen a greater scientific understanding of people with mental retardation. This has been possible due to rapid advances in psychology, medicine, biochemistry, neurosciences, and other related fields. These advances can help prevent mental retardation, provide better care for those who are already mentally retarded and enable governments to make appropriate policies.

This monograph summarizes the current state of knowledge about mental retardation. More importantly, it also describes ways and means by which better care can be provided to those with mental retardation by their families and others.

Yogeeta

HISTORICAL BACKGROUND

Cases of mental retardation are found in every community, althoughthey are referredtodifferently, suchas, *mandabuddhi* inIndia, *buddhipratibondhi* in Bangladesh, and *mandabuddika/mandamanasika* inSri Lanka. Casesofmentalretardationhavebeendocumentedinancientmedicalliteratureandinfiction.KashyapaSamhita,anancientAyurvedictreatiseonchildhood diseases, makesa specific reference to children born with lesser intellect (*buddhi*), andevenofferstreatmenttoimprovethecondition. There is mention of disabilities in Sri Lankan medical chroniclesandliterature.Onecanfind manyreferencesto disabilitiesin Jathakastories, dealing with thelife of the Buddha. Several references to weaknessof the mindare foundinthe'HolyQuran'andinawell-attestedsermonofthe ProphetMuhammad.

Overtheyears,traditionalsocietiesinMemberCountriesof theSouth-EastAsiaRegion(SEAR)ofWHOhavedealt with thesepeoplewithanattitudeoftolerance,acceptanceand resignation.Theyhavebeencaredforwithasenseofdutyand compassion.InSriLanka,somefamiliesevenconsideritta divineblessingtohave beenchosenbyGodtolookaftera specialchild.Butthismaynotalwaysbethecase. Families mayconsiderthebirthofsuchachildasamisfortune,acurse, ordestinywhichtheyhavetolivewith,leading,attimes,tothe subjectbeingtreatedwithneglect,rejection,segregationand abuse.

Many SEARMemberCountriesareundergoingsubstantial socialtransition. This includes changesincommunity and family attitudes towards mental retardation. Unlike earlier times,itmaynotbepossibleforfamiliestocareforamentally retarded memberwithoutexternalandprofessionalsupport andhelp.

Ameetingwasheldquitefarfrom Earth,"It'stimeagainforanother birth",saidtheangelstotheLord above.
"Thisspecialchildwillneedmuch love. His progress mayseemvery slow,Accomplishmentshemaynot show
Andhewillrequireextracare Fromthefolkshemeetswaydown there.
Hemaynotrunorlaughorplay; Histhoughts mayseem quite far away;
Inmanywayshewon'tadapt, And he will be known as handicapped,
Solet'sbecarefulwherehe'ssent, Wewanthislifetobecontent."

"Please,Lord,findparentswhowill doaspecialjobforyou.
Theywillnotrealizerightaway Theleadingrolethey're askedto play.
Butwiththischildsentfromabove Comesastrongerfaith andricher love.
Andsoonthey'llknowtheprivilege given
IncaringforthisgiftfromHeaven. Theirpreciouscharge,someekand mildisHeaven'sveryspecialChild."

Anonymous

MYTHS AND MISCONCEPTIONS ABOUT MENTAL RETARDATION

Despite the changing perceptions, many myths and misconceptions about mental retardation persist among large sections of the population in countries of the Region.

Myth: Mental retardation is a hereditary problem.

Fact: Only a few causes of mental retardation are hereditary, i.e. passed on from parents to children. Mental retardation is often caused by external influences, some of which can be prevented.

Myth: Bad deeds in the previous life of parents cause mental retardation.

Fact: This is completely false. Such beliefs add to the suffering of the families who are already overburdened with caring for their special children. Some communities perpetuate the myth that if one tries to remedy the illness or take treatment, the suffering will be repeated in one's next life. This results in added suffering to the patient from lack of proper treatment.

Myth: Mental retardation is caused by pregnant and lactating women not following restrictions on food.

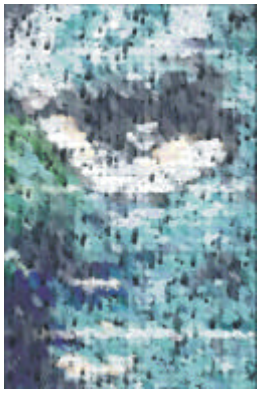
Fact: Pregnant and lactating women must maintain good nutrition for their own health and also for the health of the unborn or newly-born child. There is absolutely no basis for restricting food to pregnant and lactating women. However, some medications, if taken during pregnancy, may lead to malformations in the unborn child. Medication should be taken only on the prescription of a doctor. When consulting a doctor for an illness, women should always inform the doctor about being pregnant.

Myth: Mental retardation is infectious.

Fact: This is completely false. Mental retardation cannot be spread by touching a patient. Children with mental retardation must be cuddled and loved just as much as normal healthy children.

Myth: Tonics/vitamins/medicinescancurementalretardation.

Fact: Ifmentalretardationiscausedbyatreatablecondition, appropriatetreatmentwillcureit.However,therearenо"brain tonics" which can stimulate a damaged brain. Many unscrupulous healers and manufacturers market such substanceswithpopularandmisleadingnames,whichimply that if thesesubstancesare taken, thechild will become normal. This is particularly common in ruralareas,where quacksmarketsomemixtures,guaranteeingparentsacure. These substances frequently contain a substance called 'steroids'.These medicationsmakethechildplumperand perhaps happiertemporarily,whichmakestheparentsfeel good.Butthebasicconditionofmentalretardationisnot cured. In fact, steroids are harmful if taken for long durations.



DigitalCreativity

Myth: Brainoperationscancurementalretardation.

Fact: There are very few conditions leading to mental retardationwhichcanbecuredbysurgery.

Myth: Marriagecancurementalretardation.

Fact: This is completelyfalse.Infact,a mentally retarded person shouldbemarriedonlywiththefullconsentand knowledgeofthepartner.

Myth: Children with mental retardation become completely normalwhentheygrowuptobeadults.

Fact: Childrencanmakesubstantialprogressastheygrowup. However, it is unlikely that they will become completely normal.Eachcasemustbeassessedindividually.

Myth: Mentallyretarded adultshavepoorsexualcontroland poseadangertoothers.

Fact: Infact,adultswithmentalretardationaresexuallymore inhibited than their normal counterparts. Onthecontrary, manysuchpeoplearevictimsofsexualabuse.

Myth: Mentally retardedchildren are incapable of learning anythingandsoeverythinghastobedoneforthem.

Fact: Thesechildrenarecapable of learning, althoughhow muchtheylearnandatwhatspeedtheylearnmayvary.The harderweworkwiththem,themoretheywilllearnandmore independenttheycanbecome.Thereisnobettersolutionto theirdevelopmentthanworkinghardwiththem.

Myth: Mentallyretardedchildrenshouldnotbemadetocry foranyreasonorshouldnotbedisciplinedinanyfashion.

Fact: Allchildrenneedtobedisciplined.Everyeffortshould bemadetoteachchildrenwithmentalretardationwhatis right and what is wrong, recognizing their capacity for learningandtakingintoconsiderationfactorsbeyondtheir control.

Myth: Faithhealerscancurementalretardation.

Fact: Thisiscompletelyuntrue.Thereare manysadstories aboutparentssellingalltheirvaluablesandtheirlandonthe advice of faith healersand giving this away in charity, frequently to the faith healer. Faith healers mislead the parents.There are many alternative systems of medicine practisedinSEARMemberCountries,someofwhichclaimto havea'cure'formentalretardation.However,considerable researchisstillneededbeforetheirexactefficacyandsafety canbeestablished.

Fightingagainstmisconceptions-anexamplefrom Bangladesh

Mukti, a special education teacher working with disabled children inoneofthecentresrun by the Bangladesh ProtibondhiFoundation(BPF) inDhaka, wasmarriedanddidnothaveanychildrenfor12long years. Finally,sheconceived,butcontinuedtowork withthedisabledchildren.Herrelatives,neighbours and well-wishers repeatedly requested her to discontinueherworkandtoavoidcontactwiththese typesofchildrenduringherpregnancy,whichwas veryprecious.Attimes,shegotconfusedthinkingof the unborn child. But her husband was very cooperativeandgaveheralotofmoralandemotional support and askedher not to listen to all these superstitions. Mukti was blessed with a healthy daughter. The baby,named Ritu, accompanied her mothertoworkrightfromthedayshejoinedatthe endofhermaternityleave.Ritu,whoisnow1yearand 8monthsold,isabright,pleasantchildwithabove averageintelligence.

PreetiSnigdhaNayak

NORMAL DEVELOPMENT OFCHILDREN

Afterbirth,normalbabiescontinuetodevelopphysically and mentallytillthe ageof18years.Thisiscalledthe developmentalperiod.

Mental development occursinasequential,orderly and a predictablefashion.Normally,onewould expectbabies to developcertainskillsbycertainages.Forinstance,walking andlearningtosayafewwordscomesbytheageof1year and3months.Thesearecalled“milestonesofdevelopment”. Thesemilestonesareclassifiedinfourareas:motor(control overbodymovements),cognitive(ability tounderstandand dealintelligently with situations),social (interacting with people and learning appropriate social behaviours) and language (understanding what others say and learning to talk).

Anyonewhoisfamiliarwithbabiesknowsthattheydevelop andlearnrapidly,especiallyinthefirst3-4years.Theyarevery quickin learning during theseyears.How do theyacquire suchacapacity?Growthandmaturationofmanyorgans of thebodyisresponsibleforthis,butmostimportantly,thisis becauseofthematuration ofthebrainanditsfunctions.In otherwords,thebrainundergoesrapid maturation during theseearly years;as a consequence, babies learn and develop fast. It shouldberemembered that for acquiring theseskills,notonlymaturationofthebrain,butalsoahealthy andstimulatingpsychologicalenvironmentisnecessary.

A healthyand stimulatingpsychological environmentisnecessary forachild'sdevelopment.

WHAT IS MENTAL RETARDATION ?

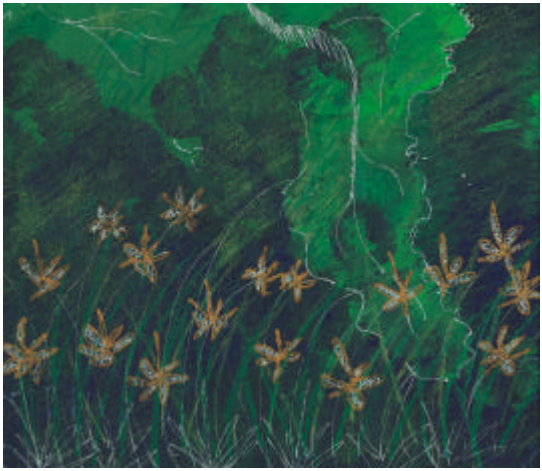
Whathappenswhenthebrainfailstomatureandgrow?

Naturally,suchbabiesfailtodevelopandacquiremilestones like normal children. Theseconditions, inwhichthere is a significant deficit or delay in thedevelopment of various mental functions from early childhood, are called developmentaldisabilities.

One can recognize different types of developmental disabilities, depending on what function or functions are affectedandhowextensiveisthelimitation.

MentalRetardation: Thisisaconditioninwhichthereisdelayor deficiencyinallaspectsofdevelopment,i.e.thereisglobal and noticeable deficiency in thedevelopment of motor, cognitive, social, and language functions. This is the commonestformofdevelopmentaldisability.Inmanyways, mentalretardation is alsorepresentative of developmental disabilitiesingeneral,initscausation,nature,andcare.

Hashanisafouryearoldboy; hestillcan'twalk independently,butcantakea fewstepswithsupport.Hecan recognizefamilymembers, butcannotshowwherehisear andnoseare.Hecanbabble (sayba-ba-ba)buthasnot learnttosayanymeaningful word.Hecan'tindicatetoilet needs.Hisparentssaythathe islikeaone-year-oldchildin hismentalabilities. Hashan hasmentalretardation.



Yogeeta

Ashaisathree-year-oldchild. Shecanspeakwell,singa song,drawapictureofacat, andeatbyherself.Butshe cannotyetwalk,andmoves aroundthehousecrawling.Her parentsreportthatshewas slowinholdingherheadupand sitting,comparedtotheirother children.Herlowerlimbsare stiffandcrossoverlike scissorswhensheliesdown. Ashahasaspastictypeof cerebralpalsyaffectingher lowerlimbs.

CerebralPalsy: Inthis condition,there is grossdelayin the developmentofmotorfunctions.Childrenwithcerebralpalsy havegreatdifficultyininitiatingandcontrollingtheirmuscles andbodymovements.Manyofthesechildrenareperfectly well in all otheraspects, such æsintheirspeech,learning abilityandsocialization.Thisdifferentiatescerebralpalsyfrom mental retardation. In addition,their legs andarms may appeartoostiffortoolimp.

The main form of treatment ofcerebral palsyis through physiotherapy and stimulation.By these methods, motor developmentcanbeenhancedandcomplications such as contractures of muscles prevented. In a smallnumber of children,medicalandsurgicalmethodscanbeusedtoreduce thestiffnesssothatmovementsbecomeeasier.

Helpisavailable...

Helpforindividualswithcerebralpalsyandtheirfamilies isavailablethroughspasticsocietiesfunctioninginmany placesin India.Recently,anorganizationdevotedto cerebralpalsy,calledIndianFamilyofCerebralPalsy,has beenstartedinHyderabad,India.

DeepashreeM.Shanbhag

LanguageDevelopmentalDisability: Somechildrendevelopwell inallotheraspectsexceptspeech.Thishappenseventhough theirhearingisnormal. Many of these childrenareableto understand what isspokentothem, but they are slowin learning tospeak.Thesechildrencan benefit substantially through speechtherapy.Thetechniquesofspeechtherapy canbelearntbyparentsandpractisedathome.Amajorityof childrenwiththisconditiongrowuptobenormal.

DigitalCreativity

Nadeemisafour-yearoldboy. Hewalksandrunswell.Hecan putonslippers,takeoffhis underwearbeforepassing stools,andhitaballwithabat. Buthecanspeakonly4-5 words:abba,ammi,na-na,and dhu-dhu(formilk).However,he canunderstandandfollow mostverbalinstructions.For instance,whentold,hecan fetchhisfather'sbagfromthe nextroom. Nadeemhas expressivelanguage developmentaldisability.

Didyouknow...

AlbertEinsteindidnot speaktillhewasfour yearsoldanddidnot read tillhewasseven.

Autism: Thisisararedisorderinwhichchildrenfailtodevelop theabilitytorelateandinteractwithpeople.Theytendtobe lostintheirownworldandremainindifferenttopeoplearound them.Theyhavepooreyecontact.Theymaydevelopsome limited s peech, but fail to use it for c ommunicating with others.Theytendtospendmostoftheirtimerepeatingthe sameactivitiesagainandagain.Themainformoftreatment for autism is behavioural training to improve social, communicative,andself-helpskills.

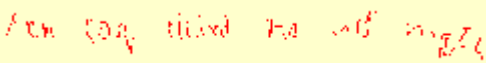
Pintu,atwo-and-a-half-yearold boy,spendsmostofhistime eitherrockingbackandforth, orcontinuouslymovinghis handsinfrontofhiseyes.He oftenkeepsrepeatinga meaninglessphrase'tittu'ina peculiarvoice.Hecanseewell, butdoesnotbothertolookand show interestinwhoisaround him.Whencalledbyhismother, hebrieflyglancesatherand goesbacktohisrocking. Inspiteoftheseproblems, hecanclimbupastooland takeouthisfavouritecookies fromatinkeptinthekitchen. Pintuhasautism.

Didyouknow...

Thegreatinventor ThomasAlvaEdison, andthefamousartist LeonardodaVinci,had dyslexia?

Dyslexia: Inthiscondition,thelevelofintelligenceisnormalor aboveaverage;yet,suchchildrenhavedifficultyindoingwell in studies.Thishappens because eventhough thechild is otherwise intelligent,hehassignificantdisabilityinlearning thethreeR'sofreading,writing,andarithmetic.Thiscondition shouldnot be confused with mentalretardation,because thesechildrenretaintheir learningabilityinotherareassuch aslanguage,sports,andsocialandartisticskills.Theyoften getunnecessarilyblamedasbeinglazyanduninterestedin studies.The problemis complicatedby their tendency to avoidschoolworkastheyfinditunrewarding.

Raju,a ten-year-oldboy,failedtwiceinclassIII.His motherandhisteacherstriedveryhardtoteachhim thespellingofsuchsimplewordsas'girl','forest'buthe stillmakesmistakes.Hishandwritingisverypoorand hardlylegible.Asampleofhiswritingisasfollows:



(Hen) (Dog) (Scored) (who) (have) (night)

Whilereading,hetendstoguessatwhatiswrittenand makesmanymistakes.Butheisverygoodinmaking friends,playingfootballandrunningerrands. **Rajuhas dyslexia.**

Thisconditioncanbecorrectedtosomeextentbyspecialized methodsofteaching.Itisalsoveryimportantthatchildren withdyslexiaaregivenfullencouragementto developtheir talentsandskillsinnon-academicareas.

Attention Deficit HyperactivityDisorder: Allchildrenareactive, butafewareoveractiveandconsideredhyperactive. They maysleeponlyafewhoursatatime.Whenawake,theyare impulsive,constantlyin motion,darting fromoneactivityto another, oftenfailingto sustain attentioninsimpletasksor games. Such children often have Attention Deficit HyperactivityDisorder(ADHD).

ADHDaffectsatleast1-2%ofallschool-agechildren.ADHDis 4-8 times more common in boys than it is in girls. Undiagnosedanduntreated,itwreakshavoconayoungster's senseof self-esteemand interfereswith his/her ability to performwellat school,tomakefriends,andtogetalongwith siblingsandparents.

S.V.Krithika

CommonmanifestationsofADHD

A child can be said to have ADHD when several symptoms mentioned below are prominently seen for many months.

- Being fidgety, restless and hyperactive most of the time;
- Having poor concentration in activities, leaving tasks unfinished, and frequently shifting from one activity to another;
- Impulsive behaviour such as often interrupting others, doing dangerous things like rushing into traffic, peeping into wells, jumping from heights, and pulling the tail of dogs;
- Being distracted from activities by minor events and happenings, and
- Easy excitability, over-talkativeness, and aggressive behaviour.

A comprehensive treatment programme taking a holistic view of the individual with ADHD is needed. This requires decisions regarding administering medication and behaviour therapy strategies. Often teacher training, parent training, family therapy or individual counselling is needed.

Conductdisorders: Conduct disorder is defined as "repetitive and persistent pattern of behaviour in which the basic rights of others or major age-appropriate societal norms or rules are violated." The group of behaviours characteristic of conduct disorder include aggressive behaviour that may cause physical harm or injury to people or animals, theft, violation of rules and destruction of property. It is believed that approximately 1 to 2% of children under 18, especially boys, suffer from conduct disorders in SEAR Member Countries.

Theintensityanddurationofthesebehaviouralproblemsin childrenhas significant repercussionsin family, social and academicareas.Conduct disorder may be associatedwith other mental disorders, including ADHD, depression and learning disorders. Severe psychosocial factors, such as familydisharmony,lowsocioeconomiclevel,harshparenting patternsandchildabuse,mayalsoberesponsible.Thestrong influenceofthemedia,especiallytelevisionandrapidsocial and family system changes, could also play a role in precipitatingandmaintainingthemorbiditylevelofconduct disordersinchildren.

During evaluation, children with conduct disorders are typicallyhostileandeasilyprovoked.Acarefulassessmentof the family, school and personal dimensions should be undertaken.Managementinvolvesa holistic approachwith emphasisonbehaviourmodificationviateachersandparents. Unchecked, conductdisordersmayleadtoantisocialtraits, substanceabuseandevencriminalbehaviourinadulthood. Prognosismaybegoodincaseswherethereissupportfrom thefamilyandthesocialnetwork.


Yogeeta

Moreaboutmentalretardation

Asnoted earlier, mentalretardation isaconditionin which thereisasignificantlysub-averagementaldevelopmentfrom birthorearlychildhood.Mostpeoplewithmentalretardation havetheconditionfrombirth.Inasmallnumber,thecondition mayoccurfollowingdamagetothebraininlaterchildhood. Thiscould,forexample,followanepisodeofbrainfever.

Mentalretardationisalsotermedasmentaldeficiency,mental sub-normality,andintellectualdeficiency.Termsthatare also usedincludeidiot,imbecileandmoron.Theseinsultingand demeaningtermsshouldnotbeused.

Generally, mental retardationisalife-longcondition.Those affected continue t o have diminished intellectual capacity throughout their lives. However, inmostindividuals with mentalretardation, those parts of the brain that are not damaged continue todevelop.Therefore,they continue to acquireskillsandabilitiesastheygrowolder,albeitslowly.

Mental retardation is not mental illness. The major characteristic of mental retardation is delay in mental development, whereas the major characteristic of mental illness is disturbance in the mental functions of thinking, feeling, and behaviour. Mental illness can occur at any age, whereas mental retardation is present from childhood. However, some people with mental retardation may also develop mental illness.

Degrees of mental retardation

Not all people with mental retardation have the same level of intelligence. The scientific method of measuring intelligence is through standardized psychological tests called IQ tests. IQ or intelligence quotient, is the percentage of intelligence a person has, in comparison to a normal person from a similar background. An IQ of 100 is considered normal intelligence. The lesser the IQ, the more severe is the level of mental retardation. Based on IQ, mental retardation can be classified into different degrees as follows:

IQ	Category
85-100	Normal
70-85	Normal but not retarded
50-70	Mild mental retardation
35-50	Moderate
20-35	Severe
Below 20	Profound


Digital Creativity

A more practical and simpler way of classifying mental retardation is to think of only two categories: mild mental retardation with an IQ range of 50-70, and severe mental retardation with an IQ below 35. Though the concept of IQ is useful in some ways, it does not always give the true picture of the abilities of the person. A related and more appropriate measure is the social quotient (SQ), in which importance is given to the acquisition of socially relevant skills.

Functioninganddevelopmentofpeoplewithmentalretardation

Table1illustratestheattainmentsofpeoplewithdifferent degrees of mental retardation in adulthood. It is clear that eventhosewithsevere mentalretardation can becomeat leastpartlyindependentinlookingafterthemselvesthrough propersupervision,careandtraining.

Table1

Adultattainmentsindifferentdegreesofmentalretardation

Degree	IQrange	Adultattainments
Mild	50-70	Literacy + Self-helpskills++ Goodspeech++ Semi-skilledwork+
Moderate	35-50	Literacy +/- Self-helpskills+ Domesticspeech+ Unskilledworkwithorwithoutsupervision+
Severe	20-35	Assisted self-helpskills+ Minimum speech+ Assisted householdchores+
Profound	Lessthan20	Speech+/- Self-helpskills+/-

Note: + meansattainable: + + meansdefinitelyattainable: +/-meanssometimesattainable

SOME FACTS AND FIGURES

Mentalretardationisacommoncondition.Insurveysin the general populationinIndiaamongpeopleofall ages,ithasbeenfoundthataround2%havemental retardation.Inotherwords,inavillageof1000people,one canexpecttofindaround20peoplewithmentalretardation. Butifoneestimatestheproblemonlyinchildren,(under18 yearsofage)therewillbeabout3%ofcaseswithmental retardationamongallchildren under18yearsofageinthe samevillage.Regardinglearningdisability,astudybyUNICEF inSriLankarevealedthat12%ofprimaryschoolchildrenhad learningdisability.AnotherreportfromSriLankaestimated that15%ofschoolgoingchildrensufferedfromsomeformof disability. A study in children (aged 2-9 years) from Bangladesh found that around 7% had some form of disability.Mentalretardation,thesecondmostcommonform of disability, was seen in around 2% of children. Severe mentalretardationinBangladeshichildren(2-9yearsold)was estimated to be around6 per1000,inkeeping with the reportsfromothercountries.In1999,thePlanningDivision, Department of Mental Health of Thailand conducted an epidemiological study on mental health problems countrywideandfoundthattherateofoccurrenceofmental retardationwas1.3%.

Mildmentalretardationismuchmorecommonthansevere mentalretardation,accountingfor65to75%ofallcaseswith mentalretardation.Lookedatinanotherway,inavillageof 1000people, of the 20whowillhavementalretardation, about15willhavemildmentalretardationandaboutfivewill havemoresevereforms.

Ithasbeenfoundthatmentalretardation,especiallymild mentalretardation,ismorecommoninruralareas,andinlow-incomegroups.Reasonslikepooraccesstohealthfacilities, under-stimulation,andunder-nutritioncouldaccountforthis observation.

WHATCAUSES MENTAL RETARDATION ?

Why does mentalretardation occur?As notedearlier, anything thatdamagesandinterfereswiththegrowth and maturation of the brain can lead to mental retardation.Therecanbehundredsofsuchcauses.Thismight happenbefore,duringorafterthebirthofthechild.Whilea fewexamples areexplainedbelow,a more detailed listof causesisgiveninTable2.

MachiPelha

Table2

Causesofmentalretardation

Category	Type	Examples
Prenatal (causesbeforebirth)	Chromosomaldisorders	Downssyndrome*,FragileXsyndrome, PraderWilisyndrome,Klinefelterssyndrome
	Single gene disorders	**Inbornerrorsofmetabolism**,suchasgalactosemia*, phenylketonuria*,mucopolysaccaridoses Hypothyroidism*,Tay-Sachsdisease **Neuro-cutaneous** syndromessuchastuberous sclerosis,andneurofibromatosis **Brain malformations**suchasgeneticmicrocephaly, hydrocephalusandmyelo-meningocele* **Other**dysmorphicsyndromes,suchasLaurence MoonBiedlsyndrome
	Other conditionsof geneticorigin	RubisteinTabisyndrome DeLangesyndrome
	Adversematernal / environmentalinfluences	**Deficiencies***,suchasiodinedeficiencyandfolicacid deficiency **Severemalnutrition*** inpregnancy **Using substances*** such asalcohol(maternalalcohol syndrome),nicotine,andcocaine during early pregnancy **Exposure*** tootherharmfulchemicalssuchas pollutants,heavy metals,abortifacients, andharmful medicationssuchasthalidomide,phenytoinand warfarinsodiuminearlypregnancy **Maternalinfections**suchasrubella*,syphillis*, toxoplasmosis,cytomegalovirusandHIV **Others** suchasexcessiveexposure toradiation*,and Rhincompatibility*
Perinatal (aroundthetime ofbirth)	Thirdtrimester(late pregnancy)	**Complicationsofpregnancy*** **Diseases*** inmothersuchas heart andkidney diseaseanddiabetes **Placental** dysfunction
	Labour(duringdelivery)	Severeprematurity,verylow birthweight,birth asphyxia Difficultand/orcomplicateddelivery* Birth trauma*
	Neonatal (firstfourweeksoflife)	Septicemia,severejaundice*, hypoglycemia
Postnatal (ininfancy andchildhood)		Braininfectionssuchastuberculosis,Japanese encephalitis,and bacterialmeningitis Head injury* Chronicleadexposure* Severeand prolonged malnutrition* Grossunderstimulation*

Note:conditionsmarkedwithanasteriskaredefinitelyorpotentiallypreventable.

Somecommoncausesofmentalretardation

DownsSyndrome: Thehumanbodyismadeupofbillionsof cells. Each cell contains 46 thread-like structures called chromosomes.InDownssyndrome,becauseofabiological erroraroundthetimeofconception,the cells cometohave oneextra chromosomei.e,47insteadof46chromosomes. Thepresenceofanextrachromosomeinthecellsinterferes withthe normaldevelopmentofthebrain,leadingtomental retardation.Downssyndromeisacommoncauseofmental retardation. It is often possible torecognize people with Downssyndromebytheirfacialappearance,characterizedby up-slantingeyesandflatbridgeofthenose.Downssyndrome occursin about1in800newbornbabies.Eventhoughitisa geneticdisorder,Downssyndromeismostoftennotinherited andcanoccurinanychild.However,itismorelikelytooccur whentheageofthemotheratthetimeofthebirthofthechild isover35years.

Mothersolderthan35 yearsofagemay considerantenatal geneticscreeningfor diagnosisofDowns syndromeinthe unbornchild.

Eventhoughpersonswith Downssyndrome havemental retardation,theypossessgoodsocialandinteractionalskills.

InheritedMetabolicDisorders: Chromosomesinthehumancells containgeneswhichcontrolgrowthandmaturationofthe brain.Someofthesearesponsibleforchemical(metabolic) reactions,whichareessentialforbraingrowth.Ifsuchagene is abnormal, it can lead to derangement of metabolic reactions and thereby cause mental retardation. Phenylketonuria is one such condition. Babies with phenylketonuria,inadditiontomentalretardation,have light-coloured hair and skin, a small head, and are prone to convulsions.

Detectionof phenylketonuriaatbirth andproperdietary treatmentcanprevent braindamageandhelp babiestogrow normally.

Maternal Rubella Syndrome: Rubellaor German measles is generally a harmless viral infection in adults, producing symptoms of mild fever, rash, andenlargement of lymph nodes. But when itoccurs for thefirst time during early pregnancy, the virusspreads to the baby growing in the mother's wombandcausesextensivedamage.Whensucha babyisborn,itislikelytohavementalretardationandvisual impairment.

Maternalrubella syndromeispreventable byimmunizingchildren withrubellavaccination (aspartofMMR vaccination).

Iodinedeficiency disordersarepreventable byuniversaliodization ofsalt.

IodineDeficiencyDisorder(cretinism): Iodineisessentialforthe normaldevelopment of unborn babies. Lack of adequate availabilityofiodinefromthemotherrestrictsthegrowthof the brain of the foetus, and leads to a condition called hypothyroidism. Babies with this problem have mental retardation,hearingimpairmentanddwarfism. In addition, theymayhavelethargy,coarsenessoffacialfeatures,rough and dry skin, feeding problems, constipation, cold extremities,andneckswellingbecauseofenlargementofthe thyroidgland.Asevereformofthiscondition,inwhichallthe featuresmentionedareverypronounced,iscalledcretinism.

Iodineoccursnaturallyin food.Butinsomeplaces,thesoil andthefoodaredeficientiniodine.Insuchplaces,naturally,a pregnantwoman'sintakeofiodineislessandthereforetheir infants would also bedeficient in iodine and manifest hypothyroidism.Iodinedeficiencyisprevalentinlargeareasin someMemberCountriesofSEAR.

Difficult/ComplicatedDelivery: Tilltheyareborn,babiesreceive theirsupplyoffoodandoxygenfromthemother.Immediately afterbirth,babiesbegintobreatheontheirown.Normally,this transitionoccurssmoothly.When,foranyreason,thedelivery becomesdifficult,prolonged,orcomplicated,oxygensupply to thebabyisdiminished.Asthebrainisverysensitiveto oxygendeprivation, thiscanresultinbraindamage.This is called birth asphyxia.Such babies may have problems in developmentsuchasmentalretardationorcerebralpalsy.

Brain Infection (Brain Fever): An important cause ofmental retardationafterbirthisbraininfectionscausedbybacteriaor viruses.Inthiscondition,childrenwhoareotherwisenormal, suddenlydevelopfever,headache,vomiting,convulsionsand lossofconsciousness.Ifthisinfectionissevere,theremaybe irreversiblebraindamageleadingtomentalretardation.Such children,whentheyrecoverfromacuteillness,arenoticedto have lost manyskillswhichtheyhadlearntearlier.Young childrenare more a t risk for brain fever inregionswhere Japaneseencephalitisandtuberculosisarecommon.

Nutrition and Mental Development: A balanced diet rich in calories, protein, vitamins and minerals is required for pregnant women and young children for normal brain development.Lack of a dequate diet can have direct and indirecteffectsonbraindevelopmentandtherebyincrease theriskofsubnormaldevelopment.

Studieshaveshownthatbirthweightisanimportantindicator ofthefuturehealthofthebaby.Ababywithlowbirthweightis more likely tohave problemsinmental development. The height and weight ofwould-be mothers andthe extent of weightgaininpregnancyareimportantfactorsdetermining birthweight.

Propernutritionofthe girlchildandgood nutritionforpregnant womancanprevent manydevelopmental problemsintheirbabies.

Yogeeta

DigitalCreativity

Commonhealthproblemsassociatedwithmentalretardation

Many children and adults with mental retardation are otherwise physicallyandmentallyhealthy,exceptthatthey havelower intelligence.Severalothers,however,frequently have other problems. The common health problems associatedwithmentalretardationareasfollows:

Behaviourproblems: Symptomslikerestlessness(continuously moving around; unable to sit in one place), poor concentration, impulsiveness, temper tantrums, irritability andcrying are common. Other disturbing behaviour, like aggression,self-injurious behaviour(such asheadbanging) and repetitive rocking may also be seen. When such behaviour issevereandpersistent,itcanbecomeamajor sourceofstressforfamilies.Therefore,attentionshouldbe paidtoreducesuchbehaviourwhileprovidingtreatmentand care.

Convulsions: About25%ofpeoplewithmentalretardationget convulsions.Manytypesofconvulsionscanoccurinvolving thewholebody,oronlyonehalfofthebody,orsuddensingle jerks leading to a fall.Convulsions, although alarming to watch,canbeeasilycontrolledwithpropermedication.

Sensory impairments: Difficulties inseeing and hearing are presentin about5-10%ofpersonswithmentalretardation. Sometimes theseproblemscanberesolvedbyusinghearing aidsorglasses,orundergoingsurgeryforcataract.

Asnoted earlier, other developmentaldisabilities,such as cerebralpalsy,speechproblemsandautism,canoccuralong withmental retardation. Persons withmanydisabilities, or multipledisabilities,poseabigchallengeintermsofproviding care.

WHAT CAN BE DONE?

Individual and family approaches

Mental retardation is generally a life-long condition and it cannot be 'cured' with medical treatment. Given this fact, what can be done and what should be the aims and objectives in providing care for these individuals? The following considerations should be kept in mind to guide actions.

Scientific evidence: Scientific research has shown that by providing the right kind of support and services, it is possible to ensure that those with mental retardation can live healthy and relatively independent lives. These services comprise many areas such as health care, early intervention, education, vocational training, and so on. Studies have also shown that considerable ill health, physical or behavioural, in people with mental retardation is caused by lack of appropriate care and is hence preventable.

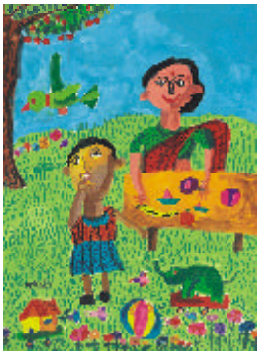
Humanistic need: As citizens of a civilized society, it is the right of people with mental retardation to lead their lives with respect and dignity. It is possible to achieve this goal by bringing about positive changes in societal awareness, attitudes and beliefs about this condition.

Family perspective: Very often, the problem of mental retardation is inseparable from the problems faced by the families. It is clear that organized services are definitely needed for families to adapt well and face the situation with confidence and the least amount of stress.

To achieve these aims, professionals from many fields, families, governmental and non governmental organizations, and society as a whole have to work together. The following principles should help in guiding and directing the development of appropriate services:

Normalization

This concept, which originated in the Scandinavian countries, has had a powerful influence. In simple terms, normalization means ensuring that the same environmental conditions of everyday life are available to people with mental retardation as they are for anybody else. It also means providing them with facilities to enable development of their full potential.



ApurbaBhattacharya

Integration

Individuals with mental retardation should become an integral part of society; they should not be isolated, segregatedordiscriminatedagainstinanyfashion.

Home-basedCarewithParentsasPartners

Researchhasshownthatthebestplaceforchildrenwith mentalretardationtogrowinistheirownfamilies,wherethey can be nurtured with appropriate stimulation. Therefore, services should be organized so that the families are supported,strengthenedandempoweredtolookaftertheir affectedmember.Familieshavedifferentneedsatdifferent stagesinthelifecycleofitsmembers(suchaschildhood, adolescence,andadulthood);thisshouldberecognizedand attempts made to fulfil these needs.Itshould also be recognizedthatfamiliesarenotjustrecipientsofservicesbut care-providers as well.Inotherwords,theyarepartnersin care.

Community-basedApproaches

Very often, servicestendtobeconcentratedinwell-to-do urban localities. To overcome this lop-sided approach, a community orientation isnecessary, sothatservicesare availabletolargesectionsofsocietyintheirownvicinity.No programme is likely to succeed without community involvementandparticipation.

Servicesforindividualswithmentalretardation

MedicalandPsychological(clinical)Services

Thefirst requirementis forappropriatefacilitiesfora good medical/healthevaluation and accurate diagnosis.Doctors should b e i n a p ositiontorecognizeandmanagetreatable disorderssuchashypothyroidism.Associatedproblemssuch as convulsions, sensory impairments and behaviour problems,canbecorrectedorcontrolledwithpropermedical attention.Itisdesirable to havefacilitiesfor psychological assessmentofstrengthsandweaknessesinthechildwhich canformthebasisforfuturetraining.

Adequateparentalcounsellingintheinitialstagesisessential. Doctors,nurses,psychologistsandsocialworkerscanmakea bigdifferencetoparentsbycorrectlyexplainingthecondition andthe optionsfortreatmentaswell asbyclarifying their doubts. Parental counselling also involves providing emotionalsupportandguidance,andstrengtheningmorale. Oncethe parentsgetagraspofthecondition,theyneedto learn appropriateways of rearing and training the child. Parents continueto need suchassistance, guidance,and supportasthechildgrowsup,especiallyduringadolescence, earlyadulthoodandduringperiodsofcrisis.

There are many claims that some drugs and herbal preparations can improveintelligence. B u t n o drugsorany othertreatmentcancompletelycurementalretardation.

Itisimportanttoensurethatparentsdonotspendalotoftheir valuable moneyandtimeinpursuingtreatmentsthatareof doubtfulornovalue.

Thereisnoknown medicine,herbal preparationor substanceto‘cure’ mentalretardation.

EarlyDetectionandEarlyStimulation

Many well-conducted research studieshaveclearlyshown thatdetectingmentalretardationatanearlystage,thatis,in infancy,andprovidingalovingandstimulatingenvironment helps t hese children todevelopbetterandpreventsmany complications.

Somemedicalconditionsassociatedwithmentalretardation canbedetectedatbirthitself.Itisalsopossibletodefinea groupofbabieswhoare“atrisk”ofhavingagreaterchanceof developingmentalretardationastheygrowup.Thesearethe babiesbornprematurely,orwithalowbirthweight(lessthan 2kg),orwhohavesufferedbirthasphyxia,orthosewhohave hadaseriousillnessintheneonatalperiod.Awell-recognized methodforearlydetectionistofollowthedevelopmentofall thebabiesfrombirthandobservewhethertheyarelagging behindconsistently.Byandlarge,mostbabieswithsevere mentalretardation canberecognizedbytheage of6-12 months.Mildmentalretardationusuallybecomesevidentby the age o f two years. Standardized methods for early detectionofmentalretardationarenowavailable,andcanbe adaptedto any culturewith proper modifications. Once a babyisdetectedorsuspectedtohavementalretardation,itis necessarytoprovideappropriatestimulationforappropriate development.

Yogeeta

Parentsshouldbealert...

- Babieswhoarepremature,orhaveabirthweightof lessthan2kg.Thosewhohadadifficultneonatal periodareatriskfordevelopingmentalretardation; theirdevelopmentneedsclosemonitoring.
- Babieswhoareslowinreachingearlymilestonesof development,suchasholdingupneck(normal = 3-4months),socialsmile(normal=3-4months), sittingwithout support (normal = 7-8months), walking without support (normal = one year 3 months), saying a few words (normal = 1 year 6 months) and social gestures such as "*Namaste*" (normal=1year6months).
- Repeatedconvulsionsinearlyinfancy.
- Babieswho areinactive,slowtoreactandlethargic.
- Childrenwhoaredependentforself-careactivities suchaseating,dressingandtoiletcontrolevenby theageof4-5years.

Babieswhoareatriskordetectedwithdelayeddevelopment should receive sensory-motor stimulation. These are techniquesbywhichparentsencourageandteachbabiesto useanddeveloptheirsensory(vision,hearingandtouch)and motor (grasping, reaching, manipulating, and transferring) faculties.Techniquesincludeactivelyengagingwiththechild bycaressing,talking,showingbrightobjects,playingtoelicit laughter, tickling, gentle massaging, bouncing, putting the childindifferent positions andplaces,usingtoysand play materialstoarousethechild'sinterest,guidingthehandsto manipulatethingsandsoon.Suchstimulationisnecessaryfor normal development. Children with developmental delay need it all the more, because they are prone to understimulation.

Manymanualsandguideshavebeendevelopedtocarryout early stimulation, for instance, Portage Guide to Early Stimulation and PreschoolIntervention forDevelopmentally Delayed Children(publishedbytheNationalInstituteforthe MentallyHandicapped,Secunderabad,India).Someofthese modelshavebeensuccessfullyadaptedtoSEARconditions.

Earlyintervention:asuccessfulventure…

Onegoodexampleofearlyinterventionforat-riskbabiesistheUNICEF-fundedproject conductedbytheAndhraPradeshAssociationfortheWelfareofMentallyRetarded,in Hyderabad,India.Allbabiesborninalargehospitalwerescreenedfor riskfactorsfor delayeddevelopment, suchas very low birth weight, birthasphyxia, birth trauma, persistent jaundice,convulsionsandcongenitalanomalies.Interventionwascarriedout for410babieswhowereathighrisk.Mostofthembelongedtoasocioeconomicallylow class.Interventionwasconductedathome,utilizingthe"homevisitor"model,alongthe lines of the Portage Project. During their weekly visits, the trained home visitors educated thefamily members in child health care, provided supportandguidance, taughtthemtheskillsofearlystimulation,andhelpedthemtoaccessmedicalservices. Theresults attheendofthreeyearswereverypositive.Only6.8%hadpersistent developmentaldelay,comparedto12%inagroupofchildreninwhominterventionwas notcarriedoutforavarietyofreasons.

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TraininginSelf-help,SocialandPracticalSkills

Normalchildrenlearntheskillsofdailylivingsuchasfeeding, dressing, toilet training, and socialskills such asplaying, mixing,andinteractingwithotherseasily,bywatchingothers andwithsomeadultguidanceandteaching.Butchildrenwith mentalretardationoftendonotlearntheseskillsontheirown. Throughsystematiceffortsandusingpropertechniques,itis possible to teach andtrainthemintheseskills.Behaviour modification techniques are very useful and effective in teaching.Theseinclude:

- **Rewarding or positive reinforcement:** Paying attention, praisingthechildandgivingsomematerialrewardsuchas sweets, candies or toys whenever the child shows desirable behaviour or makes an attempt to learn, increases thechild'smotivation tolearnappropriate and newbehaviour.
- **Modelling:** Showingthechildhowa particular activity is done andencouragingthechildtoinitiatetheactivityisa powerfulmethodofteachingnewbehaviour.Thisisbetter thanjustorallytellingorinstructingthechild.
- **Shaping:** Thismeans teaching thesimplifiedversion of a complex activity first and then graduallymakingitmore andmorecomplexatapacecomfortabletothechild.
- **Chaining:** Anactivity,suchasdressingskills,canbebroken upintoseveralsmall,sequentialsteps.Thechildcanbe taughttheseskillsstep-by-step.Veryoften,back-chaining orteachingthelaststepfirstandthengoingbackwardsis moreeffective.
- **Physicalguidance:** Ifthechildcannotlearnbymodelling,he orshe can be taught the activityby holding hands and showingthemhow the task is done.Aftermany such repetitions, the physical guidance can be slowly withdrawn so that the child learns to do the task independently.

Modern researchhasclearlyestablishedtheutilityof these behaviouraltechniquesinimpartingmanykindsofskills.

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SpeechTherapy

Speech and language are very important and highly specializedfunctionsforhumanbeings.Theyservethecrucial purposeofcommunicatingone'sownfeelingsandthoughts to others. Mental retardation is oftenaccompaniedby a significant limitation inthe development of speechand language. Research has again shown that a systematic application of speech therapy techniques is effective in promoting speech, languageandcommunication. Speech therapyisrequiredinmanychildrenwithmentalretardation.

Education

Astheygrowupandmasteractivitiesofdailyliving,children withmentalretardationneedtobeimpartededucationlike otherchildren.Goingtoschoolisessentialforthemtolearn notonlyacademicskillsbutalsodiscipline,social/interactional skills,andpracticalskillsforcommunityliving.Thoughtheyare slowinlearning,experienceandresearchhasshownthatby applyingtherightkindofeducationaltechniques,itispossible toimpartthebasicskillsofreading,writing,andarithmeticto many with mental retardation. The current approachis to educatethem,asfaraspossible,innormalschools,rather than setting up specialschools (inclusive education).This especially applies to those with milder forms of mental retardation. However, more severely retarded childrenmay benefitbetterineducationalsettingsmeantforthem(special schools).Anotherapproach,whichisinteresting,istoconduct special classes only for them in normal schools itself (opportunitysections).Whatevermaybe theapproach,itis importanttorealizethatevenchildrenwithmentalretardation need educational experience, to ensure their optimum developmentandwell-being.

A positive developmentin SEARMember Countriesisthat thereis,to a largeextent,informalorcasual integration of children with mild mental retardation in normal school settings.With some effort, it is possible tosee thatsuch children are given individual attention. This can be strengthened further byteacher training and provision of resourceteachersandresourceroomssothatmoreandmore childrenwith mentalretardation,especiallythosewithmild mentalretardation,canenterthenormalschoolsystem.This hasbeendemonstratedin manydistricts ofIndia,wherea schemeof Integrated Education of the Disabledhasbeen attempted through the joint efforts of governmental a nd nongovernmentalagencies.Recently,therehavebeenmajor initiatives in this direction in Bangladesh, Sri Lankaand Thailand.

Roleofspecialschools

Special schools have played a pioneering role in providing organized services for the mentally retarded. They are often started by parents in collaboration with other interested persons and professionals. The number of special schools is steadily increasing in SEAR Member Countries. Thoughinitiallyconfinedtourbanareas,theyarenow extendingtoruralareasinrecenttimes.Theirrolesare alsochanging;theyinitiallyfocusedonlyonproviding specialeducation,butoflatetheyhavebecomelocal resource centres and are even instrumental in bringing about a positive change, community awareness and healthy attitudes. Some special schoolshavealsobeenengagedintheextensionof servicesbeyondtheschool.

VocationalTraining

Isitpossibleforthesepersons,asyoungsters,tolearnsome vocation andbeemployed?Studieshaveshownthatthisis indeedpossibleforthemajority.Buttherearemanyhurdles. Onemajorhurdleisattitudinal-thereisacommontendency tounderestimatethecapabilitiesofthesepeople.

Potential jobs can be manual, unskilled or semi-skilled, dependingonthecapabilitiesoftheindividual.Itshouldbe rememberedthatsuchgainfuloccupationisnot onlypossible butalsohelpfulforthementalhealth,self-satisfaction,and socialstatusoftheseindividuals.Therearemanyinnovative examplesofhowthiscanbeachieved,e.g.,villagescanoffer avarietyofagro-basedopportunitiesforgainfulemployment ofthesepeople.

Whenphysicaland attitudinalbarriersareremoved andfacilitiesforlearningand opportunitiescreatedfor trainingtheretarded,the majoritycanbegainfully employed.

DeepashreeM.Shanbhag

Adultswithmentalretardationcanandshouldwork.Herearesomeexamples

Bangladesh…

A20-year-oldboywithmildmentalretardationwasbroughttotheclinicfromavillagefor problematic behaviour. He spentmost of his time roaming around the village and demandingthingsfromshopkeepers.Theparentstriedtoengagehiminfarmwork,but failed.WhentoldtopickweedsinthefIeld,hewouldalsopickthecrop.Theboy'suncle volunteeredtotrytotrainhim,afterhelearnthowtotraintheboy.Withalotofpatience andrepeatedteaching,theboylearnttodofarmworkandbecameverygoodatit.He startedenjoyinghisworkandbecameusefultothefamily.Atthesametime,histemper tantrumsanddemandingbehaviourdecreased.

India…

Inauniqueexperiment,NavjyotiTrustforvocationalrehabilitationinChennaiwasableto modify thelearningenvironmentto successfullyteachtheskills of light engineering assemblytomentallyretardedchildren.NowtheTrustregularlyhandlessuchassembly formanyindustriesoncontractual basis.Workof a high quality isaccomplished by individualswithretardationandthereisalonglistofsmallandlarge-scaleindustrieswho havebeensuccessfullyabletoutilizetheseindividuals.Somehaveevenmadeitapolicyto earmark aproportionofjobsforthem.

SriLanka…

ThemotherofagirlwithDownssyndromewasveryupsetandworriedwhenshecameto knowoftheproblem.Shekeptworryingaboutwhatthechildwilldowhenshegrewup. But,overtheyears,shenoticedthatthegirlhada flairandtalent forhandlingyoung children.Now,themotherrunsacrècheathomeandthegirldoesmuchofthecaringof children.Bothsheandhermotherlookhappyandconfident.

NetherlandsandUSA…

IntheNetherlands,adultswithmentalretardationhavebeenengagedsuccessfullyinthe manufactureofTVsetsformorethanthreedecades.

Inthe USA,peoplewithmentalretardationcandosomejobsbetterthantheirnormal counterparts.Forinstance,theservicesofpeoplewithmentalretardationwereutilizedin assemblingsomepartsofApollo11,whichwenttothemoon.Thiswasbecausetheirerror rateswerelowercomparedtonormalpeople.Normalpeoplewere morelikelytomake mistakes becauseof boredom, which was notthe case with those with mental retardation.

S.V.Krithika

ResidentialCare

Thereisnodoubtthatthebestplaceforpeoplewithmental retardationtogrowupinistheirownfamily.Thealternativeof setting up large-scale facilities, attempted by Western countriesforaboutacentury,hasprovedtobeabigandcostly blunder.

Ontheotherhand,oneissuethatisamajorsourceofworryfor parentsisthepossibilitythattheirretardedchildmayoutlive them.Thequestion,"whatwillhappentomysonordaughter afterwearenomore"keepsbotheringthemastheyandtheir childgrow older. The support ofextended families and transferofcaretothesiblings,whichwereacommonpractices earlier,maynotbepossibleinthecurrentandfuturescenario. Also, families commonly face the problem of making temporaryarrangementforcareoutsidethefamilyintimesof crisis, familyfunctions,journeysandothersituations.There are also some families in very difficult circumstances, for whomprovidingcarefortheirretarded memberbecomes impossible.Eventhefamilieswhohavea highcommitment andwhoaretakinggoodcareoftheiraffectedmemberfeel theneedtoberelievedofthestressofcareforshortperiods, toavoidburn-out.

Keeping these considerations in mind, it is necessary to establishfacilitiesfortemporaryorpermanentresidentialcare foralimitednumberofpeoplewithmentalretardation.

InThailand…

TheMinistryofPublicHealthadoptedthe"Health-for-All2000"policyandimplementedthe primaryhealthcarestrategyin1980.Servicesforintellectuallydisabledpatientswerethen reformed. These included training programmes for general practitioners, nurses, psychologists,socialworkersandcommunityhealth officers.Therewasalsotrainingat generalhospitals,communityhospitalsandhealthcentres,toeducateandtrainstaffin diagnosing mental retardation, delayed development, and in the provision of early interventionservicesandsimplerehabilitation,insteadofhavingtoreceivetheseservices onlyfromspecializedhospitals.

Inaddition,therewasatrainingprogrammeforvillagehealthvolunteersineveryvillagein thecountry sothattheintellectuallydisabledpatientswithobvioussymptomscouldbe diagnosed andtreatedlocally.The purposeof thisprojectwastoenablepatientswith obvioussymptomstoaccesstheservicesfromthepublichealthcentresclosesttothem. Villagehealthvolunteerswouldserveascasemanagers,visitingthepatientsandmaking arrangementsfornecessarytreatment.

Yogeeta

Thereisawell-known sayingthatthehomeis thefirstschoolfor childrenandthemother isthefirstteacher.This isespeciallytrueinthe caseofchildrenwith mentalretardation.

Whatthefamilycando

Therearethreeaspectsconcerningthefamiliesofpersons withmentalretardation.Thefirstisthestressestheyfaceand howtheyadapttotheproblem.Thesecondisthetrainingof parentsas co-therapistsandthethirdistheimportance of establishingorganizations of parents of mentally retarded children.

FamilyStressandAdaptation

Familiesfacealotofstressanddifficultieswhilecaringfor family members with mental retardation.They encounter differentproblemsatdifferentstages.Stressmaytakemany forms-demandsofdailycare,lackofleisuretime,emotional disturbances such as worries, frustrations, sadness, irritability, and relationship problems between family members. In addition, there is stigmatization, social embarrassment,andfinancialimplications.

However, families are not always passivesufferers.They makeeffortstoovercomethedifficultiesandtrytocopeand adjusttothesituation.Theytrytosolicitsupportandadvice fromrelatives,friends,religiouspersons,andprofessionals.

Inthisprocessofadjustment,certainthingshelpthefamilies tocopeandadaptwell.Familiesneedtogathertherightkind of information about the condition and become knowledgeableaboutit.Atsomestage,theyhavetoaccept thementalretardationinafamilymember-theyshouldalso understand that these family members will continue to develop,eventhoughataslowerpace,andthathome-based trainingcanenhancesuchdevelopment.

Itisalsoveryimportantforfamiliestopreservetheirown health,maintainfamilycohesionandharmoniousrelations. Theyshouldtryasmuchaspossibletocontinuewiththeir normallife.Theyshouldnotcutofftheirrelationshipsand contactswithfriendsandrelativesoutofasenseofshameor embarrassment.Theburdenofcareshouldnotfallonlyonthe mother;otherfamilymembersshouldalsoshareinthecaring. Familieshaveagreaterchanceofsucceedinginsolvingthe problemswhentheyworkwithasenseoftogetherness.

Families can sometimesbring about bigchanges in the society. One good example was US President John F Kennedy,whohadasisterwithmental retardation. He was responsibleforradicalchangesintheprovisionofservicesfor individualswithmentalretardationinUSA.Familieshavethe responsibilitytoprovidegoodcare,affectionandtrainingto theseindividuals,but,atthesametime,itisnotnecessary thattheysacrificeeverythingforthesakeofthechild.

Even people with mentalretardationcangiveandreceive affectionlikeothers.Ahappyfamilyisonethatrecognizesthis factandtakespleasureineventheirsmallachievements.

Some Do'sandDon'tsforparents...

- Seekinformation and clarify yourdoubts from reliablesources.
- Lookatabilitiesratherthandisabilitiesinthechild.
- Noticesuccessesandpraisethem,howeversmall thesemaybe.
- Trytolearnthetechniquesoftrainingandpractise them.
- Rememberthatthosewithmentalretardationare slowinlearning buttheycanstillbetaughtwith patience,persistence,andthecorrectapproach.
- Findoutaboutservicesthatareavailableandutilize them.
- Thereisnoneedtofeelashamedabouthaving a retardedchild.
- Thereisnoneedtoblameoneselforotherfamily membersforthechild'scondition.
- D o not overprotectthe child; a s faraspossible encouragethemtostandontheirownfeet.
- Do not waste money unnecessarily on dubious treatments,whichhavenotbeenproven.
- Contactotherparentsformutualsupport.

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ParentTraining

Initially, thetechniquesoftrainingindividuals withmental retardationweredevelopedforprofessionals.Later,attempts toteachtheseskillstoworkerswithminimalexpertisewere madeandfoundtobefeasible.Stilllater,itwasrealizedthat parentsthemselvescould be taughtthe techniques.Also, professionals realizedthatparentscame upwithideasand techniques thattheyhadneverthoughtof!Afamily,inthis way,isaco-therapistandapartnerincare.

Manyprogrammeshavebeendevelopedforimpartingthese skills to parents. Several centres insomeSEARMember Countri esnowholdregularworkshopsforgrouptrainingof parents.Somecentresin Indiahaveevolvedaninnovative approach of short-term residential family-focused intervention,especiallyforthosewithsevereandmultiple disabilities.Avarietyofeducationalandtrainingmaterialsare also available,notably,fromthe National Institutefor the MentallyHandicapped,Secunderabad(India).

ParentOrganizations

Perhapsthebestpersonswhocanunderstandtheplight of parentswithamentallyretardedchildareotherparentswho have gone through similarexperiences. When many such parentscometogether,theycanworkasagroupformany tangiblebenefitsforthemselvesaswellastheirchildren.This has, infact, happened allover theworld in the last 3-4 decades.Theseparentorganizationshavealsobeenreferred toasself-helpgroups.Themainfunctionofthesegroupsistoo meet other parents and realize thatthey are notalone, besidescollectinganddisseminatinginformation,providing supportfor'new'parents,supportingandlearningfromeach other onhowtofacesituations andsolve problems,and working towardsorganizingbetterservicesintheirlocality. Theycanalsofunctionaspressuregroupstogettheirshareof resourcesfromthegovernmentandevenbringaboutpolicy changes.

Utilityofparents/groups-amother'sperspective…

Themotherofa15-year-oldboyattendingaself-help groupforsometimereported,"Ialwaysthoughtthat itismyfatethatIshouldsilentlysufferbecauseofthe problemscreated by my son. I wouldfeel very helplessandtiredbutsomehowusedtocarryon.But thingshavechangednow.Iseeothersfacingsimilar problemsandfeelthatIamnotalone.Ifeelrelieved whenItalkaboutmyproblemsfreelyinthegroup.I have alsolearnthow totacklethe problems better andfeelmoreconfidentaboutthefuture".

Parental self-helpgroup movementin India: a bigstep forward…

In the 1970s, there were very few parents organizations in India. In 1980, WHOconducted several workshops to promote this idea. This provided the motivation for many parents, professionals, and nongovernmental organizations toformself-helpgroupsintheirownlocalities.The idea caughtonovertheyears.TheNationalInstitute for the Mentally Handicapped, Secunderabad, recognized the importance ofthis approachand provided technical and organizational support. A nationalfederation ofparentsassociations(named Parivar) was formed in 1994 andannualmeetings were held. Currently,theseassociationshaveahigh visibility and a big say in matters concerning legislation and policydevelopment at the national level.

Whatthecommunitycando

Whatdoesthecommonmanknowaboutmentalretardation? Howdoesherespondwhenhecomesacrosspersonswith mentalretardation?Doeshelookdownuponthem,ridicule themorthinkofthemasapublicnuisanceorviewthemwith fear? Ordoeshe try tounderstand the problem anddo whateverhecantohelpthem?Howcomfortabledofamilies feelwhentheyhavetotaketheaffectedmemberoutofthe house?Obviously,answerstothesequestionsmakeamajor differenceforindividualswith mentalretardation andtheir families.

Putinanotherway,thequalityoflifeofindividualswithmental retardationandtheirfamiliesdependsalotontheawareness, attitudes,andbeliefsofthecommunity.Also,thesocietyasa whole has the responsibility to ensure thattherights of people are protected andfacilitiesforcareareprovided.It followsthatactionsarerequiredatthecommunityandsocial levelstoachievethesegoals.Thisisallthemorenecessary forindividualswithmentalretardation,astheycannotspeak forthemselves.

Socialstigmaofmentalretardationanditsreduction…

- Bothindividualswithmentalretardationandtheirfamilies havetofrequentlyfacescorn,ridicule,fearandrejection. Suchastigmaarisesbecauseofthelackofawarenessand theprevalenceofmanymythsandmisconceptionsabout mentalretardation. Thesestigmatizinginfluencesmake lifemiserablefortheindividualsandtheirfamiliesandadd totheirdifficulties.
- Thebestwaytoreduceandeliminatestigmaisbyraising awarenessinthecommunityandbydispellingthemyths andmisconceptions.Thishastobedonebyacombined effortoffamilies,communityleaders,governmentaland nongovernmentalorganizations.Activitiessuchaspublic education materials, street plays, public rallies, and programmesutilizingthemassmediaaresomeexamples toachievethisgoal.
- Atthemicro-level,familieshavetolearntocopewiththeir ownfearsaboutstigmatizationandkeeptheirsociallife intact.

There areother reasons also to initiate actions atthe communitylevel.Forinstance,theexistinghealthcareand educationalsystemsmaynot be responsive,sensitive,and concernedenoughtohandletheissuessurroundingmental retardation.Whateverfacilitiesareavailablemaybedifficultto access.

Allthese considerations havepropelled concernedpeopleto develop community-based rehabilitation services for disabilitiesin general and mental retardationinparticular. There have been many successful experiments and innovations in SEAR M ember Countries in the last two decades.Notably,nongovernmentalorganizationshavetaken theleadinthisarea.


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The aimsandobjectivesofcommunity-basedrehabilitation programmesare:

- to increase the awareness of the community andto sensitizeittoissuesandbringaboutapositiveattitudinal change;
- tofacilitatebringing patients and theirfamiliesintothe mainstream;
- to mobilize community resources and enhance communityparticipationinbuildingtherequiredservices;
- toestablishaccessible,availableandaffordableservices forthemajorityofpeoplewithinthecommunityitself;
- toensurethatthesepeopleandtheirfamilieshaveasayin howtheservicesarerun,and
- to promote ownership of the programmes by the community itself sothat they continue even without externalaidorsupport.

India:SourabhaCommunity-basedRehabilitationProjectcare atthedoorsteps…

Sri Ramana Maharishi Academy for the Blind, a voluntary organization in Bangalore, started a community-based rehabilitation programme in 140 villages about 40 km from Bangalorein 1990. The programme wasfundedandpartneredby ActionAid. Themainaimwastoproviderehabilitationfacilitiesfor alldisabilitiesincludingmentalretardation,atallagesin thetargetarea.

Localpeoplewithsecondaryeducationwerechosen and trained to work as grassroots levelworkers.The main activities were survey/detection, medical evaluationandtreatment(throughcamps),community awareness, parent counselling, stimulation, school enrolment, vocational training, mobilization of communityresources,andfacilitationofsocialwelfare benefits.

This ongoing programme has undergone extensive evaluation, indicating very satisfactoryresults on a varietyofparameters.

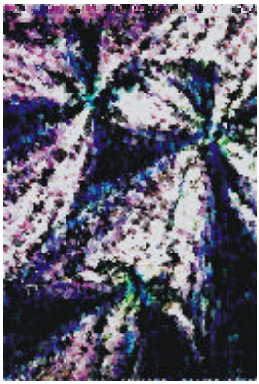
VaishaviSachinAmbre

Bangladesh Protibandhi Foundation: a successful NGO initiative…

Many NGOsareactivelyworkinginBangladeshforthe welfareofpersonswithmentalretardation.One such organizationwithagoodtrackrecordistheBangladesh Protibandhi Foundation (BPF). Started in 1984 as a parent professionalpartnership,BPFhasbeenplayinga keyroleintheareaofmentalretardation.BPFhasbeen abletoinitiateand sustainavariety of activities and programmes, which include health care and psychologicalservices,otherprofessionalservicessuch asphysiotherapyandspeechtherapy,earlystimulation programmes,aspecialschool,andshelteredworksho p. A unique programme of BPFisthe DistanceTraining Packagemeantforchildrenwithdelayeddevelopment inremoteruralareas.Thisprogrammemakes use of pictorial training manuals and guides for imparting home-basedskillstomothers,whoperiodicallycontact thecentretoensureongoingintervention.BPFalsohas a strong component of rural and community-based rehabilitation programmes, combining these with developmental activities (such as adult literacy for parentsandmicro-creditfacilitiesforverypoorfamilies). Parentempowerment throughinitiationofparentclubs hasbeenanotherimportantactivity.Inaddition,BPFhas a major rolein promoting the concept ofInclusive Education.BPFhasalsostartedcoursesforpersonnelat differentlevelstoensuretrainingand development.

InSriLanka,theSusitha ParentsAssociationconducts periodicworkshopstotrain volunteersandparentsinthe managementofpersonswith mentalretardation.The participantsareselectedfrom thecommunity,andthe workshopsareheldinmost districts.Thisprogrammehas beenverysuccessful.

Utilizing thehumanresourcesavailableinthecommunityto carryout interventions isanimportant steptoreach large sections of the needy population. Such resources would includecommunityvolunteers,grassroots-levelworkers,local peoplewithminimumeducationandschoolteachers.Ithas beenrepeatedlydemonstratedthatitispossibletotransfer basicknowledgeandskillsforthesegroupsofpeoplethrough short-term trainingprogrammes. There isalso a need for "training thetrainers"inafewspecializedcentresmeantfor this purpose. These trainerscould then train others, thus makingitamassmovement.



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Whatthegovernmentcando

Inthepublicsector,therehavebeenseriousandsustained efforts toensure a wide coverage of community-based services, especially in rural and underserved areas. The IntegratedChildDevelopmentScheme (ICDS) of Indiaisa good example with definite components of primary and secondaryprevention. Thegrassrootsworkers(anganwadi workers)underthisschemearefromthesamelocalityand areresponsibleformaternalandchild(under five yearsof age) health care with the main focus on nutrition, immunization, and health education. The scheme also includes early childhood stimulation and detection and referralofchildhooddisabilities.

AnothermajordevelopmentinIndiainthelasttwoorthree decadeshasbeentheapproachofcommunitymentalhealth, with mental retardation as a priority condition. The major objective of this movement has been the integration of mentalhealthcareintothegovernment-runprimaryhealth care system.Morerecently,a novel scheme,theDistrict Mental Health Programme has been evolved and implemented in Bellary District of Karnataka. A detailed evaluationofthismodelhasclearlyshowntheeffectiveness andutilityofthisapproach.

ThesettingupoftheRehabilitationCouncilofIndiaisarecent and ongoing attempt at sensitizing and training all the functionariesintheprimaryhealthcaresystemtotheissues concerningdisability(includingmental retardation). In this massiveproject,thefunctionariesareundergoingshort-term orientation/trainingatresourcecentresspreadalloverIndia.

While all these are very encouraging initiatives and developments, not more than 5-10% of the affected populationiscurrentlybeingservedbytheexistingservices. There is now a need for all concerned people and organizationstoworktogethertocreate,nurtureandsustain moreandmorefacilitiessothatthegenuineneedsofthis sectionofsocietyareadequatelyfulfilled.

PolicyandLegislation

Governments have the responsibilitytoprovide optimum services to adequately address the problem of mental retardation. This includes strengthening and effective utilization ofexistingservicesinthehealth,education and welfare sectors; creating new infrastructure where necessary,and encouragingandpromotingactivitiesin the NGOsectorbybuildingpartnershipswiththem.

The intent and commitment of governments to allocate resources and develop services in the area of mental retardation needs tobe expressedin theformofpolicy statementsandenactmentoflegislationatthenationallevel. Severalstepshavebeentakeninthisdirectionrecentlyin MemberCountriesoftheRegion.

InIndia,theNational PolicyforMentallyHandicapped wasformulatedin1988,whichgaveanimpetustothe developmentofPersonswithDisabilitiesAct.Coming intoforce in 1995, this Act envisages mandatory supportfortheprevention,earlydetection,education, employment and other facilitiesand social security benefitsforthewelfareofpersonswithdisabilitiesin general and mental retardation in particular. In addition, this Actprovidesforaffirmative actionand non-discrimination of persons with disabilities. In keeping with thisAct, several states in India have begun providing many socialsecuritymeasureslike disability pension,family pension, scholarshipsfor specialeducation,travelconcession,incometaxrelief and special insurance policies. Another positive development in India is the promulgation of the NationalTrustActin1999.ThespiritbehindthisActis toactivelyinvolvethe parentsofmentallychallenged personsandvoluntaryorganizationsinsettingupand running a variety of services and facilities with governmental funding. It is hoped that the implementationofthisAct will betheanswertoan importantconcernofparents,viz.,"whatwillhappen toourchildafterwearenomore".

Settingupanapexinstitutionatthenationallevelwouldbe another importantgovernmentalinvestmenttoaddressthe needsofthementallyretardedsegmentofthepopulation.

NationalInstitutefortheMentallyHandicapped(NIMH),anationalassetinIndia…

NIMH was established as an apex body in the field of mental retardationby the GovernmentofIndiain1984atSecunderabadinAndhraPradesh.Themainobjectives weretodevelophumanresources,modelsofcareandrehabilitation,andtoundertake research, documentation,andinformationinthefieldofmentalretardation.Sinceits inception,NIMHhasgrownbyleapsandbounds,withmanyachievementstoitscredit andavisibleimpactonthenationalscene.Itsmajorcontributionshavebeenmanpower development,numerousandverypopularpublicationsonearlystimulation,education, training,andrehabilitation.TheInstitutehasbeenabletodevelopinnovativemodelsof family and community-based care thathaveundergone researchevaluation,andhas functioned asaclearinghouseofinformationatthenationallevel.Recently,ithasbeen instrumentalinpromotingandsupportingtheparentalself-helpgroupmovementinIndia. Other notable activities includeanannual nationalseminaronmental retardation, an annual meet of parent organizations, Special Olympics, awareness campaigns a n d a nationalmeetofspecialemployees.TheInstitutehasmanyregionalcentresalloverIndia, mainlytoruntrainingcoursesformanpowerdevelopment.

InBangladesh...

Thereisnospecificlegislationcoveringdisability.However,apolicywasdevelopedin 1995along thelinesofUNstandardrulesonequalityof opportunitiesforpersonswith disability,anddraftlegislationisunderpreparation.Bangladeshisalsoasignatorytothe UNDeclarationofRightsforPersonswithDisabilityandtheConventionontheRightsof theChild.

InSriLanka...

TheChildren'sCharter,1991,makesacommitmenttoprovidealifeofdignityforchildren withdisabilities,andpreservetheirrights.It alsomakesspecificprovisionsindifferent areasfortheirdevelopmentandwelfare.

InThailand...

TheMinistryofPublicHealthinitiatedanewplanofservicesforpeople withintellectual disabilities in1992. This includes early detection and early stimulation programme; neonatalscreeningforhypothyroidism;jobtrainingandjobplacementforpeoplewith intellectual disabilities; self advocacy movement; parental empowerment, and educationalopportunitiesforpeoplewithintellectualdisabilities.

DebjaniMukhopadhyay

Whatthehealthsectorcando

Thehealthsectorhasakeyroletoplayinthepromotive,preventive andcurative aspects concerning mental retardation. It is a well-known fact that strong and adequate maternal and child health services in a community can decrease the prevalence of mental retardation. Its essential components are health education, spacing of pregnancies, improving the nutritional status during pregnancy, screening in pregnancy for conditions such as syphillis and Rh incompatibility, detection and obstetric care for high-risk pregnancy, proper nursing and medical care during labour, nutritional supplementation and proper immunization of young children. In addition, primary health care personnel could carry out other services such as early detection and intervention for developmental delay, guidance and counselling for families and referral to appropriate agencies for rehabilitation.

InThailand…

The Rajanukul Hospital was set up in Bangkok in 1960, to provide services for intellectually challenged patients nationwide. Patients who were admitted would undergo medical treatment, vocational training, educational and social rehabilitation. However, being the only hospital providing such services, it was unable to meet the demands and failed to fulfil the patients' needs. Admitting patients to the hospital for a long period had proved to be detrimental to the patients for a variety of reasons. For example, their adaptive behaviour decreased and the hospital's inability to discharge patients meant that it was unable to admit new patients. As a result, only a limited number of patients had access to the hospital's services. In 1980, the concept of primary health care was introduced, which included the delivery of services via community centres. This resolved many problems associated with prolonged hospitalization. Thus the Ministry of Public Health founded the Northern Child Development Centre in Chiang Mai Province in northern Thailand in 1994, which became the country's second hospital for the intellectually challenged.

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PREVENTIVE STRATEGIES

Primary prevention refers to a set of approaches that reduce or eliminate the risk of mental retardation in the community. As mentioned earlier, these concern promoting the health status of the community as a whole and affording specific protection against certain conditions. Knowledge of the causes of mental retardation can help to reduce cases by at least 25% by practising primary prevention.

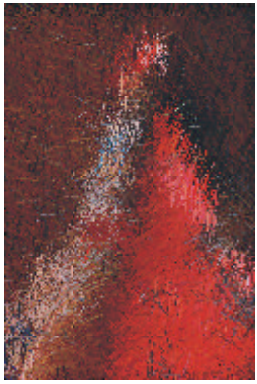
There are many methods of primary prevention. Some of these are simple, whereas others are more complicated.

Simple methods

These apply to large segments of the population and basically mean implementation of certain practical and effective interventions at the community level. A large number of these practices concern maternal and child health care. Some of the important steps are:

- Improving the nutritional status of the community as a whole, especially the girl child in order to reduce the risk factors for mental retardation such as low birth weight, and prematurity in the offspring of these children in future;
- Universal iodization of salt to prevent iodine deficiency disorders which are endemic in some parts of SEAR Member Countries;
- Administration of folic acid tablets to reduce the occurrence of neural tube defects;
- Nutritional supplementation during pregnancy, focusing on intake of calories and iron;
- Universal immunization of children with BCG, polio, DPT, and MMR to prevent many disorders having the propensity to damage the brain and thereby causing mental retardation. Rubella immunization (part of MMR) can totally eradicate the occurrence of maternal rubella syndrome;
- Avoiding pregnancy before 21 years and after the age of 35 years as complications of pregnancy and labour are more common before 21 years. The risk of Downs syndrome and other chromosomal disorders increases as the maternal age at pregnancy crosses 35 years;

- Spacingpregnancies to help themothertonutritionally replenishherselfbeforethenextpregnancy;
- Avoidingexposuretoharmfulchemicalsandsubstances includingalcohol,nicotineandcocaineduringpregnancy, especiallyearlypregnancy.Failedabortionsarecausedby chemicalsoften administered by quacks,usingharmful medicines. All pregnant women should inform their doctorsabouttheirpregnancystatus;
- Detectionandcareforhigh-riskpregnancies;
- Screeningpregnantwomenforinfectionssuchassyphilis andpromptlytreatingit;
- PreventingRhiso-immunization,asituationthatcanarise when the mother has Rhnegative blood group. The damagetothefoetuscanbepreventedbyadministration ofamedicinecalledAnti-Dimmunoglobulinimmediately afterthefirstdelivery;
- Prompttreatmentforsevere diarrhoeaandbraininfections duringchildhoodtoreducethechanceandextentofbrain damage;
- Providing an enriching andstimulating environment for children from infancy to ensure proper intellectual development;
- Chronic low-grade exposure to lead can impair brain development;stepsshouldbetakentoreducethesources of environmental pollutants (such as using unleaded petrol),and
- Healtheducationaboutthenature,causesandprevention of mentalretardation, especially duringthe formative years, canleadtohealthypracticesduringpregnancyand child-rearing.



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Advancedmethods

These are technology-intensive and generally more expensivethanprimarypreventionmeasures.Fromapublic healthviewpoint,theyare of lesserimportanceinreducing theoccurrenceofmentalretardationcomparedtothesimple measureslistedabove.Theseinclude:

- **Prenataldiagnosis/screening:** Advancesinmodernmedicine havemadeitpossibletodetectthepresenceofcertain structural and functional abnormalities in the growing embryo in early pregnancy. The pregnancy could be aborted if the embryo is found to have a serious abnormality.Someoftheseproceduresarerelativelysafe, inexpensive, and widely available.For instance,ultra-sonograminearlypregnancycandetectthepresence of severemalformationsofthebrainandotherorgans.But othermethodsinvolvinggenetictestingbyamniocentesis (removing somefluidfromtheuterus ofthemother) or chorionic villus biopsy (taking a small piece fromthe placenta of the mother) are expensive, technically complex, and n o t widely availableandhavetheirown risks.Oneshouldalso rememberthat there are many unresolvedethicalissuesinapplyingthesetechniques.

- **Neonatal screening:** There are somecauses of mental retardationforwhichdefinitetreatmentisavailableinthe formof medicinesorspecialdiets.Some examples are phenylketonuria, galactosemia, and hypothyroidism. Testsareavailabletodetectthesecondition satbirthitself. Ifthesecondition sare detectedatbirthandtreatmentis startedimmediately,theoccurrenceofmentalretardation andotherproblemscanbeprevented.Testingallnewborn babieshasbecomeastandardpracticeinmanywestern countries. However, widespread use of neonatal screening in SEAR Member Countries may not be currentlypossiblebecauseoflimitationsintheprevailing healthcare system.

- **Neonatalintensivecare:** Braindamageinverysicknewborn babies cansometimesbepreventedbyprovidinghighly specializedandtechnology-intensivecareintheneonatal intensivecareunits.Theseareveryexpensivetoset up andthecostofcareisalsoveryhigh.Fromapublichealth point of view, the impact of these services on the prevalenceofmentalretardationmaybesmall.

- **Geneticcounselling:** Prospectiveparents,especiallycouples whoalreadyhaveachildwithmentalretardationare keen to know the risk of their next child being affected. Professionaladviceto suchparentsmayhelpthemmake informed decisions about having the next child. Such geneticcounsellingcouldbeassimpleastellingparents whohaveachildwithmentalretardationcausedbybrain infectionthattheriskfortheirnextchildisverylow.Orit couldbeverycomplicatedmatterneedingseveralcostly investigationswhenageneticcauseissuspected.

Recently, therehavebeen rapid advances inthe field of genetics.Anewsetoftechniquesforthedetectionofgenetic andotherdisorderscalledmoleculargeneticshasevolvedin thelastdecade.Thoughcostly,thetechniquesarelikelyto becomeinexpensiveand becomeapplicableforwiderusein future. One example is the possibility of detecting the presence ofDownssyndromebydoingabloodtestonthe motherduringearlypregnancy.Suchtestsperhapswould becomecommoninfuture.

Levelsofprevention

ThisisanimportantapproachdevelopedbyWHO,visualizing preventionatmanylevels.Fromthisviewpoint,allservices, including earlyinterventioncanbeconsideredaspreventive measures. The levels include health promotion, specific protection, early detection and intervention, disability limitation, and rehabilitation. Table 3 showsanoverviewof how these levels are applicable in the area of mental retardation.

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Table3

Levelsofprevention

Level	Approach	Interventions
PrimaryPrevention (preventingtheoccurrence retardation)	**Healthpromotion**	Healtheducation,especiallyforadolescent girls
		Improvementofnutritionalstatusincommunity Optimumhealthcarefacilities
		Improvementsinpre,periandpostnatalcare
	Specificprotection	Universaliodizationofsalt
		Rubellaimmunizationforwomenbefore pregnancy
		Folicacidadministrationinearlypregnancy
		Geneticcounselling
		Prenatalscreeningforcongenitalmalformation andgeneticdisorders
		Detectionandcareforhigh-riskpregnancies
		PreventionofdamagebecauseofRh incompatibility
		Universalimmunizationforchildren
SecondaryPrevention (haltingdiseaseprogression)	**Earlydiagnosis andtreatment**	Neonatalscreeningfortreatable disorders
		Intervention with“atrisk”babies
		Earlydetectionandinterventionof developmental delay
TertiaryPrevention (preventingcomplications andmaximizationof functions)	**Disabilitylimitation andrehabilitation**	Stimulation,trainingandeducation,and vocationalopportunities
		Mainstreaming/integration
		Supportforfamilies
		ParentalseIf-helpgroups

Primarypreventionstrategiesremaintheoptimumsolutions inSEARMemberCountries.Not onlyarethese effective,thereisno‘cure’formostcasesofmentalretardation,andknowledge andfacilitiesforsecondaryandtertiarypreventionarelimited.