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ASSESSMENT OF PEOPLE WITH MENTAL RETARDATION

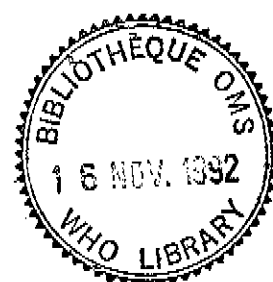
This document provides a brief review of ways of assessing the psychosocial functioning of people with mental retardation, and describes one particular "two-stage" method for carrying out an epidemiological study of mental retardation in a community. The final section points to the proper use and adaptation of tests, particularly in settings different from those in which they were developed.



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Little is known about the risk factors, incidence, prevalence or degrees of severity of childhood disability in the developing world. Before these can be studied and before appropriate prevention and rehabilitation strategies can be planned and implemented, there is a need for case-finding and assessment procedures that are low cost and cross-culturally applicable.

Representatives from WHO and the Joint Commission on International Aspects of Mental Retardation met in Paris in 1990 to discuss useful activities in this field. It was felt that the publication of a document giving guidance on the identification and assessment of mentally retarded persons would be one such activity. The document is intended especially for use by clinicians, researchers and programme directors working in communities where health and social resources are scarce.

Section I

Assessing people with mental retardation: An Overview by Professor Peter Mittler, M.A., Ph.D., C.Psychol.

Section II

Guidelines for identifying children with mental retardation in community settings, by Professor Zena Stein, M.B.B.S., B.Ch., Maureen Durkin, Ph.D., Dr P.H., Leslie Davidson, M.D., M.Sc., Z. Meher Hasan, M.S., M.J. Thorburn, M.D. and Sultana Zaman, Ph.D.

Section III

The uses and abuses of psychological tests in childhood, by Professor Philip Graham, FRCP, FRCPsych and Richard Lansdown, Ph.D., FBPsS, C.Psychol.

Section I gives an overview of general questions about the need to assess people with mental retardation and the aims and functions of assessment. It is stressed that tests should always be used positively, to meet the needs of individuals or groups: they should be viewed as the starting point for intervention rather than an end in themselves.

Section II results from ten years of preparations, development and testing of a simple screening procedure by an international team. It is a practical example of a case-finding procedure consisting of two stages. In the first stage, the Ten Questions screening instrument is administered. In the second stage, all children who screen positive plus a random sample of those with negative screening results are referred for a clinical evaluation. Standard forms have been developed for the clinical evaluation. These forms can be used along with methods described in Section I. Section II also describes purposes, area size, personnel, training of the staff and the responsibilities of the team members. WHO presents this as one possible method for carrying out a community case finding project for mental retardation. Other methods have been used for epidemiological studies of mental

retardation. This particular one however, has been marked by careful planning and evaluation throughout and deserves consideration by any group wishing to undertake such a project.

Section III is a paper prepared by WHO originally in 1983 which has been reviewed extensively by a wide panel of experts and revised accordingly. It has until now been available as a separate unpublished paper from WHO and the opportunity is now being taken to publish it along with the other two papers in view of its relevance.

The terminology used in this document has been kept consistent with that used in other WHO publications. The WHO International Classification of Diseases refers to mental retardation as the relevant diagnostic category (F.7). WHO's classification of impairments, disabilities and handicaps indicates that the primary problem for people in this area is one of mental impairment. This can lead to a variety of disabilities and, depending on the social reaction to the impairments and disabilities, these can result in handicap.

Contributors

Dr Leslie Davidson, Department of Community Paediatrics, St. Giles Hospital, Kings College School of Medicine, St. Giles Road, London SE5, United Kingdom

Dr Maureen Durkin, Columbia University, G.H. Sergievsky Center, 630 W. 168 St., New York, NY 10032, USA

Professor Philip Graham, The Hospital for Sick Children, Great Ormond Street, London WC1, United Kingdom

Professor Meher Hasan, Department of Neuropsychiatry, Jinnah Post-graduate Medical Centre, Karachi 35, Pakistan

Dr Richard G. Lansdown, The Hospital for Sick Children, Great Ormond Street, London WC1, United Kingdom

Professor Peter Mittler, Centre for Educational Guidance and Special Needs, Oxford Road, Manchester M13 9PL, United Kingdom

Professor Zena Stein, Columbia University, G.H. Sergievsky Center, 630 W. 168 St., New York, NY 10032, USA

Dr M.J. Thorburn, 3D Projects, 14 Monk Street, Spanish Town, Jamaica

Dr Sultana Zaman, Department of Psychology, University of Dhaka, Dhaka 1000, Bangladesh

ASSESSING PEOPLE WITH MENTAL RETARDATION: AN OVERVIEW

Introduction

Why do we need to assess people with mental retardation? What are the aims and functions of assessment? Are the assessment techniques developed in Western countries relevant to the needs of developing countries? If not, what kind of modifications and adaptations are needed in different cultural and social contexts? What are the main types of assessment available at present and what are their relative strengths and limitations? How and by what means is assessment to be carried out? Who should carry out assessments?

In this introductory section, an attempt will be made to address some of these questions and to give a brief overview of the "state of the art".

Why assess?

Any society that wishes to provide appropriate services will wish to ensure that the skills, abilities and needs of the individuals to be helped are properly identified not only for their sake but also to ensure the most effective use of scarce resources.

Inadequate or inaccurate assessment can lead to inappropriate decision making and placement. For example, people may be wrongfully regarded as mentally retarded when in fact their difficulties are mainly due to a hearing or communication or physical impairment. Children who make only limited progress in school may be regarded as mentally retarded without proper assessment of their intellectual functioning. In many societies, resources will then be denied to these individuals on the grounds that their mental retardation makes it unlikely that they will be able to benefit from them, thus further reducing their opportunities to learn. This is double discrimination, first on the grounds of faulty assessment and again because the ability of people with mental retardation has been underestimated.

It is axiomatic, therefore, that tests should always be used positively, to meet the needs of individuals or groups. Assessment should be the

starting point for intervention, not an end in itself.

Goals of assessment

Nearly 20 years ago, Clarke and Clarke (1973) identified a number of aims for assessment of people with mental retardation. We can now reconsider these aims in the light of the needs of developing countries and the difficulties of using and interpreting assessment data originating in other societies.

1. To describe a person at a point in time in relation to particular characteristics or functions and/or to compare their performance against norms or standards derived from a comparable population.

Assessment under this heading might be used merely for classification or research purposes and is not necessarily designed to help the individual. It has frequently been abused in order to exclude the individual from services or from access to resources; for example, an Intelligence Quotient under 50 has been used in the past to divide "educable" from "ineducable" children, a practice which has fallen into disrepute in most countries. On the other hand, IQ tests are still widely used as one of several sources of information which influence decisions on the educational needs of the child and the most appropriate type of school suited to the child's needs.

If tests are to be used to assist in the process of decision making and resource allocation, it is essential to be aware of their limitations. For example, tests and other assessment methods developed in Western countries cannot be assumed to be reliable or valid in other cultures and communities. It is almost impossible to determine the relevance or value of information derived by these means and on no account should information from such tests be used in isolation.

Tests developed and standardized in Western countries cannot therefore simply be translated and used in developing countries, nor can norms

which have been established in one setting be used to make decisions about individuals in other cultures. Furthermore, some societies are so varied and heterogeneous that it would be virtually impossible to define and find a "comparable population" in another country or culture.

For these reasons, it is currently recommended that more emphasis be placed on functional assessment of skills required in particular communities where adults are concerned.

2. To predict the status or likely pattern of development of that individual at later points in time

Although a good deal is known about the stability of IQ scores over time, it is dangerous to make administrative or educational decisions which are based on the assumptions of IQ constancy. The use of assessment to make predictions is problematic, largely because of the limited accuracy of the assessment instruments used. IQs can vary considerably over a period of time; a low IQ score on a given occasion can be unreliable for a variety of reasons — e.g. an inappropriate or unsuitable test, an unskilled examiner, assessing in an unfamiliar language or dialect, misinterpretation of results (see Berger and Yule, 1985, 1987 for more detailed discussion). Considerable research has been conducted on the predictive validity of intelligence tests, and the IQ. Much less information is available on prediction in other areas of assessment such as motor, social, language or behavioural development.

3. To draw up a profile of relative strengths and weaknesses, with a view to designing and implementing an intervention programme leading to teaching or rehabilitation.

A detailed psychological assessment can have many positive features. It can reveal strengths as well as weaknesses and indicate areas of functioning which can be used as the basis of a programme of support and intervention. Such an approach will not limit itself to the use of global tests of intelligence but will use a variety of assessments of specific skills and abilities. These can then form the point of departure for a programme of intervention or teaching. Moreover, the process of assessment will make use of the knowledge and experience of those who are closest to the person being assessed — above all the family, teachers, care workers and others in

regular contact with him or her.

Here again, it is necessary to question the validity of interpretations of particular areas of strength or weakness derived from Western tests. More appropriate is assessment based on observations of an individual's functioning in relevant community activities or enlisting the experience of family and community members who are in a much better position to assess how individuals function in different contexts. Thus, one person may be better at looking after domestic animals than younger children or in remembering spoken rather than written instructions.

4. To provide an objective means of monitoring the progress of an individual or group.

The use of tests and other forms of assessments can be used as a form of evaluation and monitoring. Intelligence tests are unlikely to be sensitive for this purpose but assessments of other skills and behaviours can be used as part of a system of ongoing evaluation — e.g. the extent to which an individual or group can function independently in self-care, such as eating, washing, dressing, in using public transport or a telephone. However, the important point to note here is that such assessments can be realistically carried out only in real life settings and by means of direct observation of the individual. Such functions can seldom be effectively assessed in artificial settings.

What do we assess?

The definition of mental retardation promulgated by the WHO stresses two essential components both of which must be present before a person can be considered as mentally retarded. These are:

1. intellectual functioning that is significantly below average
2. marked impairment in the ability of the individual to adapt to the daily demands of the social environment (WHO, 1985, page 8).

Although the assessment of cognitive and social functioning forms an essential starting point, comprehensive assessment of the abilities of an individual with mental retardation requires a more broadly based assessment of a wide range of skills and abilities. These will include assessments of other but related cognitive functions such as language and communication, perception, memory as well as ability to

learn new material. Tests of personality and other non-cognitive characteristics can also be helpful, though these are often of limited reliability.

Definitions of what is "significantly below average" must have regard to the origins of the test norms, whether the tests have been adapted for local use and whether any studies of the distribution of scores on such tests have been made in the region.

It is essential to develop schedules which can be used for observation of mentally retarded persons in various social and educational contexts, e.g. in their own homes or other residential settings, schools, day centres, community settings such as shops, public transport and leisure facilities.

An immense number of tests is available to assess a very wide range of human attributes and skills. How can we be sure that the selected test is suitable for its purpose and culturally appropriate but also developed in the light of generally accepted criteria of test construction?

Apart from the catalogues and manuals produced by the larger test publishers themselves (e.g. Psychological Corporation, Austin, Texas, USA and the National Foundation for Education Research, Windsor, Berkshire, UK) a number of encyclopaedic manuals and handbooks provide an annotated catalogue of the available tests, sometimes assessed against generally accepted scientific and psychometric criteria — e.g. details of standardization, reliability and validity, now often summarized as generalizability.

1. Buros, O. (1978) *Mental Measurement Yearbooks*. New York: Gryphon Press.
2. Levy, P. and Goldstein, H. (1984). *Tests in Education*. London and New York: Academic Press.
3. Hammill, D.D., Brown, L. and Bryant, B.R. (1989). *A Consumer's Guide to Tests in Print*. (Pro-Ed, 8700 Shoal Creek Boulevard, Austin, Texas 78758, USA)
4. Sharma, L. (1984). *National Test Library, India. Review of Tests in Print*. New Delhi: National Council of Educational Research and Training.

Readers are also referred to two excellent critical overviews of the field which provide a sound and up-to-date summary of current approaches to assessment in the field of mental retardation (Matson and Breuning, 1983; Hogg and Reynes, 1987).

It cannot be emphasized strongly enough that assessment is not carried out by tests alone. In particular, assessment of an individual's ability to "adapt to the daily demands of the social environment", calls for systematic observation in actual community settings — in the market place, in the bus queue, in situations where rapid choices have to be made, in taking messages and in the casual day to day encounters of social life. By pinpointing the nature of any difficulties experienced by the individual, a learning programme can be constructed which addresses specific needs of the individual. Such observations should be carried out by family or staff members who know the person and the community settings in which they have to function. Assessment of social competencies cannot be carried out merely by asking hypothetical questions. See Murphy (1987) for a useful summary of observational methods of assessment.

The WHO manual *Training in the Community for People with Disabilities* (World Health Organization, 1989) includes a number of scales which can be used for initial assessment of the levels of skills and functioning shown by the individual. These can form a starting point for teaching.

The manuals for specific impairments and disabilities provide many examples of training and rehabilitation programmes in day to day community settings, both for children and adults.

Assessing the environment

Assessment should not therefore be thought of solely in terms of the individual but of individuals in interaction with their environment. Assessment of the individual for purposes of support and intervention can be meaningful only to the extent that detailed consideration is given to the various environments in which the individual is living and learning. These include the immediate and extended family, the neighborhood, school, community and neighborhood, place of training or employment, all of which have a direct bearing on the opportunities to learn and to take part in the life of the community. The mobilization of community resources and environments lies at the heart of community based rehabilitation.

Who and where? Assessment in community settings

It will be clear from the above summary that assessments should wherever possible be car-

ried out by those who best know the individual. For this reason, assessment should always draw on the expertise of family and staff members who are closest to the individual and who are well placed to report reliably and in detail on their behaviour in everyday life.

Assessment should as far as possible be carried out in real life settings, rather than in the artificial environment of clinics or assessment centres. Many assessments can be carried out in the home, school or work place. This can also involve enlisting the existing expert knowledge of non-specialist personnel including parents of the individual to be assessed and also assessing the individual in the same environments in which that person is expected to function. This in turn calls for the development of assessment instruments such as checklists and observational schedules which are *ecologically valid*.

Nevertheless, there is also a place for more specialized assessment which calls for at least some degree of training and experience in test administration and interpretation. Although psychologists have often received specialist training in assessment, it has become increasingly common for them to train other professionals in the use of tests and assessment procedures. In particular, more teachers have become proficient in the use of psychological tests, as have doctors, therapists and other health professionals. In some cases, psychologists have provided supervision and support at a distance — e.g. to Portage workers (please see relevant section).

Wherever possible, psychological assessment should be part of a multidisciplinary assessment. In particular, assessment by an appropriately trained physician should be available to detect and treat medical impairments which might otherwise be overlooked. These include epilepsy, cardiac anomalies, nutritional deficiencies, sensory impairments and neurological disorders.

The International Collaborative Study on Childhood Disability has developed a Medical Assessment Form as part of the second stage professional assessment, following screening with the Ten Questions. This is described more fully in the next section.

Community based rehabilitation is essentially based on the principle of using locally based supervisors as well as parents and other family members both to assess the current strengths and needs of the individual as well as to use this information as the starting point for a programme of intervention and support. The WHO manual (World Health Organization, 1989) provides

detailed guidance on simple, low cost, community based rehabilitation for people with a wide range of disabilities. These manuals are illustrated with line drawings and can be used by people with limited literacy skills.

Detailed guidance on assessment in developing countries is also given in Baine's (1988) book *Handicapped Children in Developing Countries* as well as in *Werner's Disabled Village Children* (1987).

Baine (1988) questions the relevance of many of the tasks carried out in schools to the day to day demands of community living. He suggests that if the goals of special education and rehabilitation are to prepare the child to become a contributing citizen and to adjust to the demands and needs of the local community, radical changes will need to be made to the school curriculum to ensure that more time is spent on activities and experiences which will help the child to fulfill valued community roles and responsibilities.

Baine (1986, 1988) recommends the construction of an ecological inventory, with the following steps.

- a survey is conducted to identify the most normal settings in which an individual might function. These include family and domestic, community, recreation, school and vocational/occupational
- sub-environments in each area are then identified — e.g. the village well, the market
- key tasks within each of these sub-environments are then identified — e.g. in the market place they may be confined to simpler tasks such as carrying food home safely. More complex tasks might include selection of the right type, quality and quantity of food. Other examples include looking after animals or younger children, drawing water from the well, distinguishing good from rotten fruit, etc. Known levels of competence in these and similar tasks will make all the difference to the child being seen as a useful and valued member of the community rather than as a burden.
- observations are made of selected non-handicapped people carrying out these tasks; these will include both novices and accomplished performers
- finally, the tasks are broken down into small steps which can be organized into instructional sequences for teaching purposes.

These examples indicate that assessment of

community demands and expectations is just as important as assessment of the individual.

How to assess? Types of assessment

We can briefly summarize types of assessment under a number of headings and give a few examples of some of the more common instruments in use. These are merely illustrative and are not necessarily recommended. The choice of instruments must depend on the purposes of assessment, on the cultural and social context and on a knowledge of the strengths and weaknesses of the available assessment materials.

Individually administered tests of general intellectual functioning

A number of individually administered intelligence tests have been in use for some 50 years. Although standardized many years ago, many have been revised and restandardized and translated or adapted for use in countries very different from those in which they were originally developed. These tests are essentially normative in nature, that is the performance of each individual is compared against a comparable population of similar age and background and the results expressed quantitatively in terms of extent to which the scores deviate from those of the normative population. Many intelligence tests such as the Wechsler scales for children and adults are constructed around a mean IQ of 100 and a standard deviation of 15 points; degrees of mental retardation are assessed in terms of the number of standard deviations units below the mean. Thus an IQ of 70 is two SDs and an IQ of 55 three SDs below the mean. These measurement units reflect the relative frequency of a given score in the general population, expressed in percentile points; for example, an IQ of 70 points is found in two per cent or less of the population, one of 55 occurs with a frequency of around 0.1 per cent.

The use of individual intelligence tests has been heavily criticized in the field of mental retardation on a number of grounds:

- they have often been used to deprive people of services;
- they provide little or no information which can be used as the basis of a programme of teaching or rehabilitation;
- their general accuracy, reliability or validity are too low to justify important decisions

about individuals, as distinct from findings based on the study of large numbers.

These problems may be particularly evident at the extremes of the distribution of intelligence and also for very young children for whom prediction is particularly hazardous.

Despite these criticisms, it is now being argued that the continued use of the major tests is justified, provided certain conditions are met:

1. that the administration of the test is seen as merely one contribution to the process of providing support or services
2. that the test is administered and interpreted by a properly trained and experienced person
3. that the test is suitable both for the individual and for their particular environment and circumstances

A great deal of information is available about the uses and abuses of intelligence tests in general and in the field of mental retardation in particular.

In a major review, Berger and Yule (1985) conclude that the continued use of intelligence tests in the field of mental retardation is justified by a number of considerations, including the following:

1. Tests can provide standardized opportunities for observing both the individual and the nature of his/her performance
2. Tests can provide an index of cognitive functions that has concurrent and prognostic implications
3. Tests can be in the interests of the person assessed, if they find previously unknown cognitive strengths — e.g. high non-verbal scores in a child without spoken language or if they highlight areas of weaknesses which had not previously been suspected (e.g. memory difficulties, evidence of deterioration of one or more cognitive skills).
4. Tests are useful for monitoring progress of individuals or groups.

Among the best known tests in this general category are:

The Wechsler Intelligence Scales

Separate scales are available for pre-school, school age children and for adults (Wechsler, 1974, 1981, 1989). Thus, the WISC-R verbal scale has subtests for Information, Vocabulary, Arithmetic, Similarities and Comprehension;

the Performance subtests are Block design, Picture Completion, Picture Arrangement, Object Assembly and Coding. As the test standardization only begins at six, the pre-school WPPSI may be more appropriate for use with children who are mentally retarded.

A great deal of research has been done on the possible psychological and clinical significance of verbal-performance discrepancies and of specific sub-test patterns. Although the test has a high degree of reliability and validity and is probably still the most widely used individual intelligence test in Western, English-speaking countries, its use in other settings is problematic.

The British Ability Scales (Elliott et al., 1983) and Differential Ability Scales (Elliott, 1990)

This is a relatively new test developed in Britain but now re-standardized and adapted for use in North America as the Differential Ability Scales. The BAS includes a total of 23 separate scales assessing specific psychological functions and educational attainments from which an overall IQ can be calculated. The scales are grouped to measure functions such as Reasoning, Speed, Spatial Imagery, Short Term Memory, Perceptual Matching and Retrieval and Application of Knowledge.

The Stanford Binet Scales of Intelligence (Terman and Merrill, 1937, 1960; Thorndike et al., 1986)

This test is now little used in the field of mental retardation, mainly because of its verbal bias, though this is less marked in the 1986 revision. It should in any case be used only for children. The latest version yields the following scores:

Verbal Reasoning
Abstract/Visual Reasoning
Quantitative Reasoning
Short Term Memory
Composite Score

The Bayley Scales of Infant Development (Bayley, 1969)

The Bayley test has separate scales for mental and motor development and has been widely used for young children between two and 30 months.

The Merrill Palmer Scale (Stutsman, 1931)

The Merrill Palmer was first developed 60 years ago and therefore has norms which are invalid today. Nevertheless it is still widely used for the

assessment of young mentally retarded children, partly because of its non-verbal items (e.g. form boards) and partly because allowance can be made for refused or omitted items. The test remains popular with children.

Developmental checklists

In contrast to a standardized individually administered test, a developmental checklist provides the basis for a structured interview with an informant, such as a parent or close relative, teacher, staff member, work supervisor, etc. The accuracy of such an approach clearly depends on the reliability of the informants and how well they know the individual being assessed (see Kiernan (1987) for a critical review).

These checklists can take two forms:

- normative — i.e. they compare the individual with a comparable population of similar age and background
- criterion-referenced — i.e. they are concerned with whether or not the individual shows competence in particular skills or sub-skills, without comparing one individual with another. In practice, checklists can have both normative and criterion-reference functions.

An advantage of checklists is that they can be developed locally including culturally appropriate milestones of development. Checklists developed in Western countries can seldom be used in other regions without major modifications both in terms of the items and their standardization. WHO has a protocol and methods of analysis for developing such locally appropriate checklists and creating normative data for them (MCH/MNH.86.1).

Amongst the disadvantages of developmental checklists are the following:

- Children with severe mental and multiple impairments may not follow "normal" developmental sequences
- The developmental order of the sequences may not be correct for normally developing children
- Western norms may be different.

Some developmental checklists have been designed to form the starting point for a programme of intervention; others can be used as free-standing assessment instruments only.

A very large number of checklists is available

(see review by Raynes, 1987), of which the following are merely a few of the better known examples:

The Vineland Social Maturity Scale

(Doll, 1965; Sparrow et al., 1986)

The Vineland was first designed some 70 years ago to assess levels of social functioning, ranging from ability to dress and wash oneself to using public transport independently. The Vineland has proved most useful in the assessment of children who do not or cannot cooperate in one to one assessment but is of limited value for adolescents and adults. An overall Social Age can be calculated which could then be compared with estimates of Mental Age. The scale can be completed quite quickly with the help of a knowledgeable informant. The items are relatively crude and the scale would normally need to be supplemented with a more detailed assessment. The most recent revision contains some 300 items in fields which include communication (receptive, expressive, written), socialization (interpersonal, playing, leisure and coping), motor skills (gross and fine) and maladaptive behaviours.

Adaptive Behaviour Scales

(Nihira et al., 1974)

The ABS scales were published by the American Association on Mental Deficiency in response to the need for an instrument to assess levels of social competence and community adjustment, particularly in adults. They have since been extensively researched and refined and have also been adapted for use in other regions, including Asia.

Part 1 is concerned with Adaptive Behaviour and includes independent functioning; physical development; economic activity; language development; numbers and time; domestic activity; vocational activity; self-direction; responsibility and socialization. The ABS can be scored by reference to US norms developed for age groups and also for degree of mental retardation but has also been adapted for use in other cultures. Part 2 is concerned with behaviour disturbances.

The Progress Assessment Charts

(Gunzburg, 1977)

The PAC scales have been widely used in Europe for over 30 years and have been translated and adapted for use both with children and adults. The PAC is an inventory of skills in four core areas — self-help, communication, social-

ization and occupation. The results are represented in a series of concentric circles, the inner circle representing the lowest and the outer circle with the highest levels of achievement in relation to the likely demands of community adaptation. The PAC was designed as a starting point for a programme of social education, since it graphically identifies gaps in social competence in relation to the likely demands to be encountered by the individual.

The Portage Guide to Early Education

(Bluma et al., 1976)

Portage is one of the most successful models of assessment and intervention for young children. Originally developed in rural areas of the USA, it is now used and adapted in many developed and developing countries. The essence of the Portage programme lies in its involvement of the family both in assessment, decision making and day to day teaching of the child in the home setting. The process begins with a joint assessment of the child by the parent and home visitor.

The Portage checklist is divided into six sections, each containing between 45 and 140 individual items — infant stimulation, socialization, language, self-help, cognitive and motor. The language checklist was later revised (White and East, 1983). Each assessment result can be linked to a specific activity card which makes concrete suggestions on how the child can be helped in the home to reach goals identified in the assessment. The home visitor may demonstrate a teaching technique or activity but it is the parent who assumes the role of teacher, the home visitor acting as support to the parent on weekly or fortnightly visits. There are now many encouraging reports of the success of this approach in developing countries (e.g. White and Cameron, 1988; Yamaguchi et al., 1990; see also Kiernan, 1987 for a critical evaluation).

Parental Involvement Project Developmental Charts

(Jeffrey and McConkey, 1976)

The PIP charts were originally designed for use by parents of young mentally retarded children but have since been widely used in schools and nurseries.

The PIP charts are divided into sections on physical development (mobility, climbing, coordination); social development (feeding, toileting, cleanliness, dressing, independence) eye-hand development (reaching, grasping objects) and development of play (drawing, social play, imitative play, make-believe play, picture

books); language development (expressive language, using language, imitation of sounds; understanding; non-verbal communication).

A distinctive feature of the charts is that each sub-section begins with the "terminal item" (e.g. walk independently). If that item is not passed, the questions assess the immediately preceding skill — i.e. this is a top down rather than a conventional bottom up assessment scale.

Pathways to Independence Scale
(Jeffree and Cheseldine, 1981)

This scale is constructed along similar lines to the PIP charts but its content is suitable for the assessment of adolescents and young adults. Sections cover eating and drinking; domestic tasks; cleanliness and health; clothing; giving information; use of information; time; money; freedom of movement; use of amenities.

Paths to Mobility in Special Care
(Presland, 1982)

This schedule is particularly useful for the fine grain assessment of motor skills in children with profound and multiple impairments. It also provides linked activities for the selection of teaching objectives.

Child Disability Questionnaire
(Belmont and Clarke, 1981)

The CDQ-22 was developed in the context of the international collaborative study of childhood disability coordinated by Stein, Belmont and their colleagues at Columbia University, New York. It is intended as part of a more detailed professional assessment which follows the initial screening investigation using the Ten Questions (TQ) described in detail in the next section of this document.

The 1987 version of the CDQ-22 is used as part of a structured interview with a parent or informant who knows the child well. Questions are concerned with the child's early history and current status in sitting, walking, seeing, hearing, ability to feed, wash, toilet and dress, play with other children, contributing to household tasks, as well as detailed questions concerning understanding and use of speech and language and progress in school.

Tests of other psychological functions

In this section, brief reference will be made to a number of instruments which aim to assess psychological processes and functions not covered

by more conventional tests. The aim here is to illustrate alternative approaches to the content and the methodology of assessment. Tests of physical and sensory functioning in children with mental impairments are reviewed by Sebba (1987). None is included in this review.

The Behaviour Assessment Battery
(Kiernan and Jones, 1982)

The BAB is explicitly designed for individuals with profound levels of mental retardation. It consists of 13 sections concerned with visual inspection; visual tracking; visuo-motor coordination; auditory responsiveness; exploratory play; search strategies, perceptual problems solving; social behaviour; communication; self-help skills. The titles of these sections reflect the aim of the BAB in tapping basic components of behaviour such as visual tracking, since these are essential prerequisites to most of the behavioural landmarks identified in more conventional tests. Items concerned with search strategies and perceptual problem-solving are influenced by Piaget's work on the development of stages of object permanence, i.e., when the child understands that an object continues to exist even though it is no longer in sight.

Many BAB items are formal tests in so far as the child is confronted by objects or situations to which a response is required. The test can be administered over a protracted period.

The Uzgiris-Hunt Ordinal Scales of Psychological Development
(Uzgiris and Hunt, 1975; Dunst, 1980)

These scales are also strongly influenced by the work of Piaget and are specifically designed to assess very early levels of development between 0 and 24 months.

The scales aim to assess the following domains: progress in visual pursuit and permanence of objects; means for obtaining desired environmental events; imitation (vocal and gestural); operational causality; construction of object relations in space; schemes for relating to objects. Further experimental items and revisions were later added by Dunst.

Parts of these scales have also been used for the purpose of assessing just one of these domains. For example, Coupe and Levy (1985) developed an approach to the assessment of object schemas, in which the child's response to a series of objects is recorded within a Piagetian framework; this is then followed by suggestions for activities designed to help the child to reach

the next stage of sensori-motor development. See Hogg (1987) for a critical review of Piagetian tests.

British (Peabody) Picture Vocabulary Test
(Dunn et al., 1982)

This is essentially a test of vocabulary comprehension, especially suitable for non-speaking children. The child is shown a test booklet with four line drawings on one page and is asked to point to or eye point a named picture. It covers an age range from 3 to 19 years. The BPVT is available in both short and long versions.

The Reynell Scales of Language Development
(Reynell, 1977)

These are individually administered tests, one scale assessing comprehension and the other expressive language for children between one month and six years of age. A special scale is available for children who can only point.

The Sentence Comprehension Test
(Wheldall et al., 1979, 1989)

This test is in the same format as the British Picture Vocabulary Test but assesses the child's comprehension of sentences of gradually increasing length and complexity. The child has to point to one of four pictures which corresponds to the stimulus sentence spoken by the examiner. A Punjabi version is available. The age range of the test is from three to five years.

Assessment of behaviour disturbance

Behaviour disturbances and psychiatric disorders are more frequently found in people with mental retardation than in the general population. A number of rating scales have been developed to assess the nature and frequency of these difficulties (see review by Leudar and Fraser, 1987).

Adaptive Behaviour Scales
(Nihira et al., 1974)

Part 2 of the ABS contains items on 14 domains of disturbance concerned with behaviours which are violent and destructive, self-abusive, stereotyped, antisocial, rebellious, untrustworthy, sexually aberrant, hyperactive, withdrawn, unacceptable vocal, interpersonal or eccentric habits. The assessment concludes with a disturbance profile.

Disability Assessment Scale
(Holmes et al., 1982)

The second part of this scale addresses behavioural anomalies and contains 23 items rated on a three to eight point scale, weighted to take account of the frequency and seriousness of the behaviours. The scale particularly reflects the authors' interests in autistic conditions.

Items include: wanders and runs away, screams, temper tantrums and verbal abuse, disturbs others at night, difficult or objectionable personal habits, scattering or throwing objects around, anti-social or delinquent behaviour, sexual delinquency, quality of social interaction, imaginative pretend play or other symbolic activities, repetitive symbolic activities, choice of activities, simple stereotypies, elaborate routines, immediate or delayed echolalia, repetitive speech.

Linking assessment to intervention

The assessment methods and instruments listed in this report are only a small sample of what is available. Some of them have been developed for purposes of classification or research, others for broadly diagnostic purposes. Similarly, the use of tests should always have a clear aim and purpose. Testing for testing's sake is to be discouraged and is rarely in the interests of the individual being tested.

In recent years, assessment has been used more purposefully as the first step in the design of a programme for help or support for the individual, as in CBR and Portage. On the other hand, assessment should also be concerned with the various social environments in which the individual is likely to be living and learning, since it is these environments that can produce the obstacles to more independent living. This includes not only buildings but policies on access for disabled people to the whole range of community resources.

A number of publications provide an explicit link between assessment and rehabilitation, though several of these are geared to the needs of adults rather than children (Wilcox and Bellamy, 1987; Ford, 1989).

The following section of this document provides more detailed information about an approach to assessment and screening in the community which has been extensively used in developing countries.

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SECTION II

GUIDELINES FOR IDENTIFYING CHILDREN WITH MENTAL RETARDATION IN COMMUNITY SETTINGS

THE TWO-STAGE SYSTEM

Introduction

In communities where professional resources are scarce, a major obstacle to the assessment of children with mental retardation is the identification of the children at risk. In a developing country many children may never have attended school or received medical services; these are the two major sources of referral in developed countries (Stein, 1975; Stein and Susser, 1980; Stein, 1981; Frycys, 1984). The Two Stage system was devised to meet this situation and has now been tested in several developing countries. The Ten Questions (TQ) serves as the first stage (screening tool), whereby children likely to need fuller investigation can be selected. Assessment tools such as those reviewed in Section I may then be employed, as appropriate, as a second stage. This screening procedure meets an urgent need, in communities where resources are scarce, as a means of identifying children most likely to benefit from Community-Based Rehabilitation (CBR) or other intervention for disability.

Any method of case identification that is to be recommended for use in developing countries must be inexpensive, simple, rapid (because of the large numbers of children to be screened or evaluated), and reasonably accurate (Durkin et al., 1990). These requirements are difficult to satisfy in any one method. Reviews of census data have indicated that the use of a single question asking whether anyone in the household is disabled may miss mental retardation which is not highly visible, and differentially under-enumerates disabilities in women and children (Chamic, 1983).

Another low cost method that has been advocated is to ask community key informants (e.g., community leaders, teachers, healers, midwives) to identify all disabled persons or children in the community. This method was tested in several countries and found to be highly inaccurate, since many of the children identified were from communities other than those under study, while most of the disabled children in the communities studied were not identified by key infor-

nants (Belmont, 1984; Thorburn et al., 1991). Again, children with disabilities that are not physically obvious are likely to be overlooked by key informants.

An alternative approach involves two stages. The first stage is a door-to-door visit by community workers to identify possibly disabled children, on the basis of a screen such as the TQ. The second stage consists of follow-up assessments of selected children by professionals or semi-professionals. This approach has the most to offer to researchers and service providers working in less developed countries because it relies on resources that are locally available in those countries; namely, non-professional community workers who administer the screen. Professional resources are used with maximum efficiency, since only samples of children (most of whom have screened positive) are referred to the second stage. Initial research suggests the TQ provides a sensitive screen for severe mental retardation in 2 to 9 year-old children (Belmont, 1986; Zaman et al., 1990; Thorburn et al., 1992). The TQ also inquires about seizures, motor disorders, and visual and hearing problems. If the screen is to be used for children older than 9 years, it should first be tested.

The screening and assessment process

Preparation

Selection of Site(s)

The sites selected depend in part on the purposes of the study. If a primary purpose is rehabilitation, the selection of communities to be surveyed should be dictated by the existence of, or potential to develop intervention programmes. All households with 2 to 9 year-old children in residence within a community or cluster site should be included in the survey. If estimation of prevalence within an area is a goal of the survey, a cluster sampling strategy may be employed (Levy and Lemeshow, 1980). In any case, the research plan should include guidelines

for referring identified children to appropriate services.

Rapport with the community

In the experience of research workers planning a community study, it is important to become familiar with the sites to be surveyed and their resources beforehand (e.g., educational and health services, how best to publicize the study). It would be useful for the project director or field supervisor to contact local leaders at each site to inform them about the study, to solicit their cooperation, to discuss the benefits the survey might bring to the community, and to find out about possible difficulties.

During the course of the survey, the project director should organize the preparation of a brief description of the communities and the areas selected for the study, so as to provide an understanding of the context in which the study was done.

The geographic area

The area in which the team will work must be chosen next, bearing in mind that it is quicker and easier to identify retarded children than it is to provide a meaningful and ongoing service; survey team should make sure not to outrun its capacity to deliver such a service.

All households in a chosen site that include at least one 2 to 9 year-old child should be visited. It will be necessary to map the study area at the outset.

Possibilities for rehabilitation of the children assessed

Before initiating the screening in a community a plan must be developed to provide appropriate referrals, whether to CBR programmes or elsewhere, for children found at stage II (professional or semi-professional assessment) to be impaired, cognitively or otherwise. A Rehabilitation and Referral Form (Appendix D) is used to focus the attention of the assessment team on the prospects for rehabilitation. The Rehabilitation and Referral Form (RRF), by encouraging local workers to record the families' experiences of rehabilitation systematically and using a common form, makes it possible to obtain general data on service needs, from which all would benefit.

Personnel, training, responsibilities (adapted from Belmont, 1980)

The Project Director: The project director must take overall responsibility for the project in each region or country. This person would preferably have experience both in survey work and in childhood disability. His or her responsibilities include administrative matters, selection of the survey areas and sites, soliciting cooperation from community leaders at each site, and recruitment and supervision of the professional staff. It is assumed here that either the project director, or the field supervisor, or both, have some ongoing responsibility for providing training and supervision for services in the region.

Field Supervisors: Each project will probably require one chief field supervisor and one assistant field supervisor. The field supervisors should have a detailed as well as a broad understanding of the whole project. As they will assume responsibility for a variety of tasks, it is important that they have the capacity to communicate with many different kinds of people and have the organizing ability needed for the smooth operation of the field work. As full-time workers on the project for a year or more, they will be in direct contact with both the project director and the community workers.

These are the supervisor's duties:

- participate in selecting community workers and in their training and supervision;
- plan and coordinate all house-to-house visits;
- assign interviewers to specific locations. Emphasize that each interviewer must visit every household within her/his location;
- follow up on unsuccessful or incomplete interviews and record reason for failure to complete the interview, if needed;
- report regularly (at least weekly) to the project director on the progress of the study;
- ensure that the questionnaires are filled out precisely, accurately and completely;
- try to take account of the sensitivity of residents and of the parents of disabled children, and the feelings of the disabled children themselves;
- by example and by training, ensure that the community workers under his or her supervision understand, respect, and are helpful to parents and children;
- keep a diary throughout the duration of the project of major decisions made and the actual timetable and procedures that were followed.

Community Workers: Recruitment, Qualifications, Training: The interviewers are community workers who are able to read and write. They will usually be native to the areas being visited. The interviewers are directed and supervised by the project director and the field supervisor. The community workers interview mothers or other guardians and complete one screening questionnaire (Ten Questions, TQ, Appendix A) for each 2 to 9 year-old child in the community (as well as any additional forms chosen for a particular survey; see, for example, Appendix E).

It would be best if the workers were:

- residents of the community or familiar with it. (unless there is reason to believe community residents will be viewed with suspicion or otherwise unsuitable as interviewers and that non-resident interviewers would be preferable;)
- interested and knowledgeable about children;
- experienced in interviewing;

Note: in some settings, women may be more suitable than men as interviewers.

Training of the Community workers: During training, the community workers should be instructed in:

- 1) The purposes of the study
 - explain its general purpose;
 - explain the role of the community worker in rehabilitation/ intervention;
 - emphasize that the community worker can make a significant contribution when rehabilitation/intervention is discussed by the review team.
- 2) The nature of severe disabilities
 - describe how such children might behave;
 - discuss (preferably with the advice/participation of the project director) some of the problems of children and parents related to severe disabilities;
 - discuss some of the ways in which help can be offered;
 - stress the need for confidentiality.
- 3) General interviewing techniques
 - how to approach the household;
 - how to explain the purpose of the visit (this might be made standard for all by preparing a written introductory statement);

- how to achieve a relaxed and friendly atmosphere;
 - how to handle refusals (report to field supervisor, complete refusal form).
- 4) The forms and questionnaires to be used
 - help the interviewers to become familiar with all forms they will use;
 - go over each question, discuss why it is being asked, and the significance of the answer;
 - explain the need for asking the question exactly as written and for asking every question even if the answer seems obvious;
 - instruct the interviewers how to record: household number, mother number, child number. These numbers constitute each child's unique ID number. This information should be the first thing entered on all forms in the spaces provided.
 - 5) Practice interviews
 - training of interviewers can include role playing in the initial phase;
 - each interviewer should carry out practice interviews in at least one household;
 - the completed forms of the practice interviews should be reviewed in detail by the field supervisor and the group of interviewers;
 - uncertainties about any procedures or forms should be clarified;
 - review how answers should be recorded.

Producing the forms

The questionnaires to be read to the parents need to be translated from English to the local language or languages of the community. It is important that the translations are done carefully and accurately. The accuracy of the translation should be verified by having the translated version "backtranslated" into English (by someone who has not seen the original English version) to detect possible errors. If problems are detected, corrections should be made in the original translation. This process should be repeated until a satisfactory translation of all forms is achieved. A sufficient quantity of all forms (including those for the assessments at stage II) must be copied. You may want to duplicate each of the different types of forms on different color paper.

Project meetings, etc.

In preparation for the study, the field supervisor should meet with the project director to discuss the project in detail. Together they should:

- outline a timetable;
- decide on specific procedures for training community workers;
- compile a list of tasks to be carried out and who will do them;
- arrange a regular meeting time for the two of them and keep notes about all decisions. These notes should be kept available for consulting at any time. They will also assist in answering queries that may be raised both during the fieldwork and later during the analysis, and will be handy for writing reports.

It is useful for the field supervisor to carry out trial interviews before the training of the community workers begins, and to complete some of the survey forms.

Ten Questions (TQ): Instructions for Stage I

At the outset, you want to ensure that a sample of some of the children who screened "negative" are assessed at Stage II. This is particularly important if estimation of prevalence is a goal of the study. One way to ensure this is to mark a sample of TQ forms (for example, every eighth form) by writing an X in the large box at the end of page 4, before distributing TQ forms to the interviewers. All children whose TQ form has an X in this box will be asked to come in for assessment, regardless of whether their TQ results are positive or negative.

One TQ should be completed for each 2-9 year old child in the household.

Fill in the child's name, the date of the interview, and the identification number. Also, the name or code of the interviewer.

Questions concerning child's age:

- if date of birth is known, fill in the information;
- if date of birth is not known, but informant seems to know age in years, write that age in the space provided;
- if informant has doubts about the child's age, ask her how old she thinks the child is and record as "age as estimated by mother".

Fill in the answers the informant supplies to the remaining questions on the page.

As you turn each page fill in the child's ID number, in case the pages become separated.

Read each of the main questions on the TQ to the mother or other guardian as written and check 'yes' or 'no' depending on the answer she gives. Ask the questions in a calm, friendly way. If the mother gives an answer that indicates the child may have a problem, ask the "probe" questions that follow that question, and circle the appropriate responses.

The rules for referral for assessment are summarized at the bottom of the last page of the TQ. If a problem is reported for one or more questions, the child is to be referred. If the child is to be assessed, the interviewers should inform the mother or guardian and ask for her or his permission. If the survey is to be the starting point for a CBR programme, other interviews regarding functional abilities can also be conducted on TQ positive children.

The review by the assessment team: Instructions for Stage II

Time and place of examination

In consultation with the assessment team the project director will determine when the examinations might best be conducted. In some situations, you need to plan for a weekly visit of the team to examine children identified in the previous week. In other circumstances, the team may prefer to complete all the examinations in one block of time. In any case, the examinations for a given child should be completed within two weeks after the TQ was given. Similarly, you should decide where the examinations can be held (health center, classroom, other).

Forms to be used

The forms to be used should be selected at the outset. The revised Child Disability Questionnaire (CDQ-22 — Appendix B) can be used to guide the assessment of cognitive impairment. Other instruments selected by the evaluator should also be used if possible. The Medical Assessment Form (MAF) can be used if a medically trained practitioner is available (Appendix C). A procedure manual accompanies the MAF and is available to those interested. The assessment concludes with the Rehabilitation and Referral Form (RRF, Appendix D) which focuses on the rehabilitation needs and resources, and the development of rehabilitation and referral plans.

The cover pages should be filled out by the

field supervisor or the project director, as much of it as possible before the examinations. Particularly important for later analysis are the identification codes that appear on each page of every form. These codes are needed to link the information for each child collected on different forms.

Assessment procedures

The team evaluates each child referred without knowing whether the child was positive or negative on the TQ. If resources permit, all children selected for assessment are examined by a psychologist who will complete a CDQ-22, (Appendix B) and by a physician who completes the MAF, (Appendix C). The psychologist may use other instruments (for instance, of the kind mentioned in the Overview Document) to measure cognition as well as adaptive behaviour. The medical evaluation consists of a history and physical examination, which includes screening for vision and hearing abnormalities. For all children with diagnosed problems the assessment team completes one Rehabilitation and Referral Form. The results of the assessment need to be discussed with the parents or guardians.

Though the forms have been tested and found reliable in several settings, the reliability of local data that are collected should, if possible, be tested. To do this, the community worker would readminister the forms on a subsample of children about 2 weeks after the initial interview. Comparisons of the responses given on the two occasions allows for evaluation of the reliability of the data collected on these forms. In addition every effort should be made to include a method for establishing reliability between different interviewers, both within countries and between countries.

Consensus evaluation

The entire assessment team will meet regularly (daily or weekly) to discuss their evaluations of all children examined. If a discrepancy exists between assessments of mental retardation by different examiners, a consensus diagnosis will be made. This is recorded at the bottom of the last page of the MAF if used.

Rehabilitation

Plan

When the examinations are finished, the team will meet with the community worker and to-

gether with the parent they will discuss each child with identified disabilities and plan whatever help might be given. The community worker should bring along the child's survey and screening questionnaires. The WHO rehabilitation manual, *Training in the Community for People with Disabilities* (World Health Organization, 1989) or other intervention programmes can be used for the detailed planning of home training.

The Ten Questions (TQ) as a screening instrument

The Ten Questions is a screening tool originally developed by an international team of psychologists and psychiatrists (Levy and Lemeshow, 1980; Belmont, 1986). Each question has a simple 'yes'/'no' response format. A screening result is positive if any one or more of the Ten Questions elicits a problem, and negative if responses to all questions are normal.

The original Ten Questions was modified to test whether the instrument could be used in children as young as 2 years. For this purpose an alternative version of Question 9 on speech is to be asked if the child is 2 years of age. Thus, the TQ (Appendix A) is intended for screening disabilities in 2 to 9 year-old children and includes two versions of Question 9: one is to be asked if the child is between the ages of 3 and 9 and the other if the child is 2 years old.

As a screening tool, the TQ is not intended to provide diagnoses, but to select a sub-sample of the population in which the prevalence of disabilities is likely to be high. This sub-sample should then be followed to stage II to obtain a more definitive assessment.

The TQ may also be used as one component in epidemiologic surveys to investigate the prevalence and causes of mental retardation in young children. It is designed to benefit from the different experiences of users, so that every community in which it is used may contribute to improving it. For this use, it is imperative that a sample of children screened negative are assessed at Stage II to detect false negative results.

The questions are administered as a face-to-face interview with a parent or other adult who is familiar with the child. After this the team and community worker meet with the parent, and develop a rehabilitation plan. The community worker assists in the execution of the plan, and arranges follow-up assessments by the team.

The TQ is designed to detect moderate and severe ("serious") developmental and sensory

disabilities, seizures and speech problems. Because of the focus on serious problems, only a small proportion of children in a community (3-15%) would be expected to have a positive response on one or more questions. Six questions are meant to detect learning problems (mental retardation or cognitive disability) (items 1, 4, 7, 8, 9 and 10). There is one question for each of visual (2), hearing (3) and motor (5) problems and one on seizures or fits (6).

Although the primary purpose of the TQ is detection of mental retardation, the whole TQ should be used (and not just the questions related to cognitive disability). This is for several reasons:

1. The symptoms and signs of the six disabilities overlap;
2. Many children with serious developmental disabilities have other disabilities as well;
3. CBR programmes in unserved communities should cater to all disabilities;
4. Community workers and families may be confused and resentful if some children are omitted when others are included;
5. Recent studies are showing that the TQ items on vision and hearing may be the only positive ones in mentally retarded children (Thorburn et al., 1992).

The TQ has two features intended to enhance its appropriateness and usefulness across cultures. One is that the questions are very general and concern abilities acquired by children in all societies. Instead of asking about specific behaviours, such as whether or not the child can fetch water or eat with a fork, it asks "Does the child have difficulty walking or moving his/her arms?" (Question 5). Another feature intended to make the instrument universally applicable (i.e., to reduce its dependence on the norms of any particular culture) is that many of the questions ask the parent to compare the child's behaviour to that of other children his/her age, rather than to some external reference standard. For instance, Question 7 is: "Does the child learn to do things like other children his or her age?"

Instruments for use at Stage II: Further comments

The purposes of the second stage are to give the best assessment possible (given available resources) of the presence or absence of specific

impairments and to develop an appropriate rehabilitation and referral plan. It is at this stage that the issues discussed in Section I of the present document become relevant, and capable of further study. For example, in recent studies in Bangladesh, Jamaica and Pakistan, the psychologists adapted existing assessment instruments (such as the non-verbal scales from the Stanford-Binet 1985 edition, the Woodcock-Johnson Test, and others) (Thorburn, et al. 1992) and in some cases developed new scales for use in each culture (for example, separate normative adaptive behaviour scales were developed for assessing adaptive behaviour in Bangladesh and Pakistan) (Zaman et al., 1990; Durkin et al., 1992). A version of the Child Disability Questionnaire (CDQ-22, Appendix B) (Belmont, 1981), can also be used to provide guidance in the clinical assessment of mental retardation. For the paediatric assessments, a medical assessment form (MAF, Appendix C) and procedure manual were developed. The diagnosis of mental retardation should be made jointly by the psychologist and paediatrician after both have examined the child separately, and it is recorded on the last page of the MAF along with other medically determined diagnoses.

While the level of skill required of the door-to-door interviewer (stage I) is not high, the level of skill required at the second (assessment) stage is an area of active study and great importance. Thus, Dr M.J. Thorburn (in Jamaica) and Dr Naila Khan (in Bangladesh) have specifically sought to test the limits of specially trained community workers, in terms of skills in assessment, on the one hand, and prescribing and evaluating rehabilitation on the other. In Jamaica, Dr Thorburn is testing the ability of community workers to make assessments of disability and devise rehabilitation plans on the basis of the TQ and a brief "Handicap Questionnaire". In Bangladesh, Dr Khan is evaluating the performance of community workers in making Stage II assessments on the basis of the CDQ-22 and an "Observation of Function" (Section II of the MAF, Appendix C). Communities will have different resources and limitations, and will want to experiment.

Future developments and research

Service and research are seen as partners in the Two Stage system. The training of local teams in fieldwork, second stage assessments, keeping

records, initiating follow-up and planning rehabilitation, provide both the initial stimulus, and the encouragement and job satisfaction for team members. The technology of the microcomputer is also helpful to the approach. In our experience, computer entry of the screening and assessment data is feasible, both in terms of human skills and monetary costs, even in countries with the most limited resources. At the local level, it integrates the work, providing teams with feedback on their achievement. Beyond the local level, it provides a regional, national and international link, that counteracts the sense of isolation, burn-out, and discouragement that understandably affect many research workers in developing countries.

Research into many aspects of prevention and care may build on the basis of the Two Stage procedure. These could in theory include clinical studies (identifying and describing new entities, or adding to descriptions of known conditions), epidemiological studies (to identify incidence, prevalence, specific geographic or cultural endemic or epidemic areas, relative and attributable risks) (Durkin et al., 1992), studies of specific causes like lead exposure or iodine deficiency, evaluative studies of services or service providers (the working of Community-Based Rehabilitation; the assessment skills of workers), psychometric or child behavioural studies. Research would typically be initiated by interested investigative teams, who would work with others using the Two Stage system. In this way, a cadre of research workers and a range of communities could join in common endeavors.

At the present time, research and development of the Two Stage system for screening, assessment and referral for rehabilitation is coordinated by Dr Maureen Durkin, the Sergievsky Center, Columbia University in New York in collaboration with Ms Meher Hasan and colleagues in Karachi, Dr Marigold Thorburn and colleagues in Kingston, and Dr Sultana Zaman and colleagues in Dhaka.

In addition to the assessment instruments, forms for the household survey and for describing each community surveyed have been developed for use in the collaborative studies carried out in Bangladesh, Jamaica and Pakistan. For epidemiologic studies, these forms provide information on potential risk factors for childhood disability. For example, a Mother-Child Form is used to collect background information about the mother of the child, including her age, educational background, and pregnancy his-

tory. The Household Form provides information on the socioeconomic status. Appendix E lists the forms developed specifically for use in the collaborative studies; these have been translated into several languages and are available for anyone interested in participating in the research.

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Appendices

- A. Ten Questions (TQ)
- B. Child Disability Questionnaire Revised (CDQ-22)
- C. Medical Assessment Form (MAF)
- D. Rehabilitation/Referral Form (RRF)
- E. List of forms used in the Two-Stage Method of identifying cases in the community

APPENDIX A
TEN QUESTIONS (TQ)

Fill in this information before asking the TEN QUESTIONS

Interview number _____

Child's name _____

Child number _____

Household number _____

Child's sex: boy (1) girl (2)

Age Birthdate (if known) day/month/year / / OR

Age in years as given by mother OR

Age as estimated by mother _____

How old was the mother at the birth of this child?

(Enter age in years, estimate if not sure)

Does the child attend school now? no (1) Yes (2)

Number of live births to mother: _____

Birth order of this child (e.g., 1 = first born, 2 = second born) _____

Who will answer questions about this child? mother (1) father (2) other (3)

Is informant one who mainly takes care of this child? no (1) yes (2)

Can informant read a newspaper? no (1) yes (2)

Does informant work outside the home? no (1) yes (2)

Are the parents of this child related to each other? no (1) yes (2) don't know (9)

(blood relatives before they married)

Go to next page and ask TEN QUESTIONS exactly as written. Circle the answer given.

TEN QUESTIONS

1. Compared with other children, did the child have any serious delay in sitting, standing or walking? yes* no
2. Compared with other children, does the child have difficulty seeing, either in the daytime or at night? yes* no
3. Does the child appear to have difficulty hearing? yes* no
4. When you tell the child to do something, does he/she seem to understand what you are saying? yes no*
5. Does the child have difficulty in walking or moving his/her arms or does he/she have weakness and/or stiffness in the arms or legs? yes* no
6. Does the child sometimes have fits, become rigid, or lose consciousness? yes* no
7. Does the child learn to do things like other children his/her age? yes no*
8. Does the child speak at all (can he/she make himself/herself understood in words; can he/she say recognizable words)? yes no*
9. **For 3 to 9 year-old children ask:** yes* no
is the child's speech in any way different from normal (not clear enough to be understood by people other than his/her immediate family)?
For 2 year-old children ask: yes no*
can he/she name at least one object (for example, an animal, a toy, a cup, a spoon)?
10. Compared with other children of his/her age, does the child appear in any way mentally backward, dull or slow? yes* no

Interviewer: Answer the question below by circling one of the three options. The questionnaire result is positive if the response to any one or more of the Ten Questions has an asterisk (*) next to it. If no response has (*) next to it, then the result is negative.

Should this child be referred for professional evaluation?

1. No, because the questionnaire result is negative and there is no (x) in the box below.
2. Yes, because, although the questionnaire result is negative, there is an (x) in the box below.
3. Yes, because the questionnaire result is positive.

For data entry only:

Does the box below contain an (x) yes no

APPENDIX B
**CHILD DISABILITY QUESTIONNAIRE REVISED
(CDQ-22)**

Information regarding background, administration and coding instructions can be found in Belmont, 1981.

Instructions: Ask these questions to the parent or guardian of the child. Insert the child's name into the questions where indicated (*name*).

1. How is _____ (*name*) growing up? Compared to other children about the same age as _____ (*name*)?
 - 1 just like other children his/her age (or advanced), OR
 - 2 a little slow, OR
 - 3 very slow: acts like a much younger child?

2. Let me ask about **sitting** alone. Compared to other children did _____ (*name*) sit alone (without being propped)?
 - 1 when children usually sit (or earlier), OR
 - 2 somewhat later than other children, OR
 - 3 very much later than other children, OR
 - 7 does not apply, child does not sit, OR
 - 9 don't know (*specify reason*) _____

3. Now, **walking**, compared to other children did _____ (*name*) walk without being helped (that is, when no one had to hold his/her hand or he didn't have to hold on to things)?
 - 1 when children usually walk (or earlier), OR
 - 2 somewhat later than other children, OR
 - 3 very much later than other children, OR
 - 7 does not apply, child does not walk, OR
 - 9 don't know (*specify reason*) _____

4. Compared to other children, would you say that _____ (*name*) started to talk?
 - 1 about the same age as other children (or earlier), OR
 - 2 somewhat later than other children, OR
 - 3 very much later than other children, OR
 - 7 does not apply; child cannot talk, OR
 - 9 don't know (*specify reason*) _____

5. Can _____ (*name*) do things for himself/herself? Like eating, for example: can _____ (*name*) eat by himself/herself? Would you say,
 - 1 yes, he/she feeds himself/herself, OR
 - 2 yes, but very untidy and needs help, OR
 - 3 no, he/she has to be fed.

6. Does he/she have bowel bladder control or is he/she toilet trained?
 - 1 yes, as well as others his/her age, OR
 - 2 not consistent, OR
 - 3 no.

7. Does _____ (*name*) behave like other children his/her age? Would you say
- 1 yes, OR would you say,
 - 2 no, he/she acts strange? (If no, in what way is his/her behaviour strange?)
-
8. Does _____ (*name*) speak clearly? Is it easy to understand him/her when he/she speaks? Compared to other children about the same age, would you say
- 1 _____ (*name*) speaks clearly enough to be understood by anyone, OR
 - 2 not too clearly: is easily understood by people who know him/her but not by others, OR
 - 3 it is very difficult to understand what he/she says, OR
 - 7 does not apply: child cannot speak.
9. When you say to _____ (*name*) "Do this or that", can he/she understand? Would you say
- 1 yes, _____ (*name*) understands what I ask him/her to do as well as other children the same age, OR
 - 2 yes, _____ (*name*) understands what I ask him/her to do but I have to point or repeat the instruction, OR
 - 3 no, he/she is not able to understand even the simplest instruction.
10. Can _____ (*name*) answer your questions properly? Would you say
- 1 yes, he/she can answer as well as other children the same age, OR
 - 2 yes, but it is difficult for him/her to always answer properly: I have to repeat my questions or ask them in a different way, OR
 - 3 no, he/she cannot answer questions.
11. Can _____ (*name*) tell you in his/her own words what has happened? Would you say
- 1 yes, he/she tells me about things just as other children the same age would, OR
 - 2 yes, but he/she frequently points and gestures but says very little, OR
 - 3 no, he/she cannot let me know what has happened.

Does _____ (*name*) have any of these characteristics? (Circle 1 if no, 2 if yes)

	No	Yes	
(12)	1	2	very small head
(13)	1	2	very large head
(14)	1	2	very short stature
(15)	1	2	does not look like a normal child
(16)	1	2	paralyzed (weak or absent movement in the arms or legs)
(17)	1	2	makes strange movements
(18)	1	2	can't sit still
(19)	1	2	very aggressive
(20)	1	2	difficult to manage
(21)	1	2	seems much behind other children the same age
(22)	1	2	other (please list) _____

I. History**A. Perceived problems**

Ask the parent: **Is there anything about your child that worries you?**

Examiner: If yes, inquire about the problems and complete the table below. After recording the information for one problem area, ask about all other problem areas and complete the table. When no problem is perceived in an area, circle No and leave the remaining boxes blank for that area.

If no, to the first inquiry, still ask specifically about each problem area and complete the table.

When more than one option in the table seems to apply, enter the main one in the box and write the codes for other in () to the right of the box. In the box for family history, enter the smallest number that applies.

Problem area	Does the parent perceive a problem? (circle no or yes)		Approximate age at onset in months at birth = 888 d/k=998 (e.g. at 1mo=001) (estimate if exact age of onset is not known)	Event associated none=1 parental=2 birth trauma=3 fever, infection=4 injury=5 malnutrition=6 other (specify)=7	Treatment received none=1 modern only=2 folk only=3 both=4 d/k=8	Family history none=1 parent=2 sibling=3 grandparent=4 1st cousin, aunt, uncle=5 other blood relative=6 d/k=8
Walking: If yes, describe	no	yes	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using hands: If yes, describe	no	yes	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hearing: If yes, describe	no	yes	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vision: If yes, describe	no	yes	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Speech: If yes, describe	no	yes	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Seizures: If yes, describe	no	yes	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Learning: If yes, describe	no	yes	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other: If yes, describe	no	yes	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Additional comments:

B. Family

Are the parents of the child related to each other?

no = 1 yes, as uncle and niece = 2 yes, as first cousins = 3
 yes, as second cousins = 4 yes, as distant cousins = 5 unknown = 8

C. Seizures

Ask these questions whether or not the mother said her child has seizures when asked about "perceived problems". Probe to find out the frequency of seizures, if these are associated conditions and find out the setting in which they occurred.

Codes for questions 1 through 4 below: no = 1 yes = 2 unknown = 8

1. Did (does) the child have febrile fits (fits with fever)?

2. Did the child have other provoked fits (fits with dehydration, shigella, meningitis, toxins, trauma (within 24 hours of trauma)?

3. Did the child have breath holding spells (loss of consciousness, in setting of anger, pain frustration, or crying)?

4. Has the child ever had *unprovoked afebrile* seizures?
 If yes, please describe. If no, skip to section D.

5. If the child has had *unprovoked afebrile* seizures, how frequent and how current are they?

never = 1 >1 total but none in past 12 months = 3 unknown=8
 only 1 ever = 2 >1 total and ≥ 1 in past 12 months = 4

6. Does the child get medication for seizures?

Code medications: no = 1 yes = 2 unknown = 8

If yes to any, explain:

Phenobarbital
 Dilantin/Phenytoin
 Other Western
 Traditional/herbal

D. Pregnancy (for birth of this child)

Enter the correct numbers for gravidity, parity, stillbirths and spontaneous abortions that applied at the time of this child's birth. Gravidity is defined as the total number of pregnancies before this child (and counting the child). Parity is defined as the total number of actual births before this child (and counting this child).

Gravidity
 Parity
 Stillbirths
 Spontaneous abortions

When the mother was pregnant with this child did she have:

no = 1 yes = 2 unknown = 8

High blood pressure?
 Bleeding 1st trimester?
 Infection/Fever 1st trimester?
 Other health problems?
 Did she have antenatal care?
 Has she ever had a goiter?

* Do not include here problems with veins, pyelonephritis, moderate vomiting or mild conditions.

E. Birth

Where was the child born?

home = 1 hospital = 2 clinic/birth center = 3 other = 4 unknown = 8

Was it a single birth?

single birth = 1 twins = 2 triplets or more = 3 unknown = 8

Was the baby born at 9 months?

yes = 1 no >1 month early = 2 no >2 weeks late = 3 unknown = 8

How long was the labour?

<24 hours = 1 ≤24 hours = 2 unknown = 8

Who assisted in delivering the baby?

trained midwife = 1 TBA/dai = 2 doctor = 3 family member = 4
other = 5 unknown = 8

Were there any difficulties at birth?

no = 1 yes = 2 unknown = 8

If yes, explain:

In what position did the baby come out?

head first = 1 bottom first = 2 foot first = 3 cesarian = 4 unknown = 8

Did the baby cry immediately?

yes = 1 no, but in <5 minutes = 2 no, after > 5 minutes = 3 unknown = 8

Did the birth attendant have to do anything to the baby to make it breath?

no = 1 yes = 2 unknown = 8

If yes, why:

Was the baby taken away from the mother?

no = 1 yes = 2 unknown = 8

If yes, why:

If the baby was kept in a hospital, for how many days was it kept there?

What was the birthweight in grams? 9999 = unknown
(if given in pounds, write ___ lbs and ___ oz here, then convert to grams)

How big was the baby at birth?

about the size of most babies = 1 smaller than most babies = 2
bigger than most babies = 3 unknown = 8

Did the child have any difficulties in the first four weeks?

no = 1 yes = 2 unknown = 8

- Seizures
- Infection
- Trouble feeding
- Yellow colour
- Tetany
- Diarrhea
- Difficulty breathing

F. Nutritional history

Was the child breast-fed and for how long?

no, never = 1 yes, <1 month = 2 yes, 1-6 month = 3 yes, 7-12 month = 4
 yes, 13-18 month = 5 yes, 19-24 month = 6 yes, >24 month = 7 unknown = 8

When did the child start bottle feeding?

never = 1 within 1st month = 2 1-6 month = 3 7-12 month = 4
 13-18 month = 5 19-24 month = 6 after 24 month = 7 unknown = 8

At what age was solid food introduced?

3-6 month = 1 7-12 month = 2 After 12 month = 3 Not yet = 4 unknown = 8

Can the child feed himself or herself? (*assess in accordance with local cultural norms*)

yes, skillfully (with spoon/fork or fingers) = 1
 yes, but unskilled (i.e. like a baby) = 2
 no, must be fed = 3

G. Developmental history

At what age did the child walk without help or holding on?

(*Note: codes 4 and 5 do not apply to children under 3 years*)

by 18 month = 1 by 2 years = 2 between 2 and 3 years = 3 by 3 years = 4
 later than 3 years = 5 not yet = 6 unknown = 8

At what age did the child first use single words with meaning (other than names, hello or bye-bye)?

(*Note: codes 4 and 5 do not apply to children under 3 years*)

by 18 month = 1 by 2 years = 2 between 2 and 3 years = 3 by 3 years = 4
 later than 3 years = 5 not yet = 6 unknown = 8

At what age did the child first put two or three words together?

(*Note: codes 3 and 4 do not apply to children under 3 years*)

by 2 years = 1 between 2 and 3 years = 2 by 3 years = 3
 later than 3 years = 4 not yet = 5 unknown = 8

H. Medical history

Note: use local expressions when discussing with the informant the diseases and medical problems mentioned in this form.

Immunizations: Refer to the child's immunization record if the mother brings it with her.

Has the child ever been immunized for:

yes, complete = 1	no = 3	unknown = 8	Polio	<input type="checkbox"/>
			Whooping cough, Diphtheria (DPT)	<input type="checkbox"/>
			Tetanus toxoid	<input type="checkbox"/>
			TB (BCG)	<input type="checkbox"/>

Ask the following question even if information on specific immunizations is recorded above.

Has the child had any immunizations?

yes = 1 no = 2 unknown = 8

Explain _____

Note: If the mother answers yes to any of the medical problems mentioned in the next few pages, inquire specifically if the event was the cause of any of the problems described by the mother in the beginning of the interview. If so, write in this section and also on page 2? in the column called "Event Associated".

Note: For the remaining questions in medical history: If the answer is yes, enter the approximate age of the child in months when the event occurred. If the event occurred in the perinatal period, enter 001 for age. If approximate age is not known enter 998 for age. If the answer to the question is not yes, leave the spaces for age blank.

Has the child ever had a bad infection in the brain, meningitis or encephalitis? Age in months

no = 1 yes = 2 unknown = 8

If yes, describe:

Has the child ever had a major injury such as the following? (read all choices):

Motor vehicle accident	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Other vehicle accident	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Near drowning	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Fall (1 level to another)	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Burns (not minor)	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

If no, enter 1 and leave age blank

If yes, indicate type of treatment and age.

no = 1 in hospital = 2 outpatient = 3

home care = 4 unknown = 8

If yes to any, describe:

Has the child ever lost consciousness after an injury to the head? Age in months

no, never = 1 yes, < 10 minutes = 2 yes, < 1 week = 3

yes, < 1 month = 4 yes > 1 month = 5 unknown = 8

If yes, describe:

Additional comments on history:

II. Observation of function (complete for all children)

Instructions: Observe the child carry out the 7 tasks listed below.

As the child and informant come into the room:

1. Observe the child walking at least 5 steps into room. Watch carefully, looking for limp asymmetry of gait, toe walking, ataxia, involuntary movements, and atrophy of contractures.
2. Welcome the child and observe the response; does he or she hear, make an appropriate social response, smile, act shy, speak?
3. Invite the child to squat and to pick up a tiny object, such as a bead, coin or raisin (defined size), using each hand in turn. Observe carefully for fisting, asymmetry in grasp, absence of pincer grasp, or difficulty in seeing the object.
4. Observe the child as he/she stands up: Does he/she need to use hands to get to an upright position? (proximal muscle weakness).
5. Elicit speech by asking the child questions such as "What did you pick up?" "What is that?" (point to a raisin, chair, etc.) "What is this called?" (point to nose, ear, foot, etc.) "What is your name?" Watch for problems in hearing, speech and comprehension.
6. Ask the child to point to body parts (eyes, mouth, etc.). Observe the problems in hearing and comprehension.
7. Give the child paper and pencil and ask him/her to draw something. Scribble (for 2 year old) or draw shapes: circle (for 3 year old), square (for 4 through 6 year old), diamond (for 7 through 9 year old). Observe fine motor function and comprehension.

Rate the child in the following areas after observing the above 7 tasks:

pass = 1 fail = 2 uncertain = 3 no response = 9

Gross motor	<input type="checkbox"/>
Fine motor	<input type="checkbox"/>
Hearing	<input type="checkbox"/>
Vision	<input type="checkbox"/>
Speech (motor)	<input type="checkbox"/>
Speech (language)	<input type="checkbox"/>
Comprehension	<input type="checkbox"/>

Then have the child undress for the rest of the examination.

Complete the physical examination (Part IV) for all children.

Some children must have the neurological examination (Part IV) in addition to the physical.

Use the criteria outlined below to determine whether or not to complete the neurological exam for this child.

Criteria for determining which children must have the neurological exam

Give the neurological exam if:

1. The child fails or scores "uncertain" in any of the 7 areas rated above, or
2. Any of the following are true:
 - a. the informant mentions that the child has had any neurological sensory or cognitive problems.
 - b. the physician notes microcephaly, macrocephaly or any atrophy on the physical exam.
 - c. the physician suspects hearing or vision impairment.

Physician: Do you think, based on the interview with the informant and this brief observation that the child has a neuromuscular, vision, hearing or cognitive impairment?

no = 1 yes = 2 uncertain = 8

Please do not change your answer to this last question after completing the rest of the examination.

Additional comments on the observation of function:

III. Physical examination (complete for all children)

A. Rate the child's general appearance as:

overnourished = 1 well-nourished = 2 no subcutaneous fat = 3
 diminished muscle mass = 4 no fat and edematous = 5 uncertain = 8

B. Rate the presence of the following conditions: no = 1 yes = 2 uncertain = 8

Hair	Brittle/dicoloured	<input type="checkbox"/>
	Sparse	<input type="checkbox"/>
Skin	Scars (burns)	<input type="checkbox"/>
	Weeping sores	<input type="checkbox"/>
	Ulcers	<input type="checkbox"/>
	Cheilosis	<input type="checkbox"/>
Head	Microcephaly	<input type="checkbox"/>
	Macrocephaly	<input type="checkbox"/>
Face	Hypertelorism	<input type="checkbox"/>
	Epicanthal folds	<input type="checkbox"/>
	Flat midface	<input type="checkbox"/>
	Abnormal nose	<input type="checkbox"/>
	Facial weakness	<input type="checkbox"/>

<p><i>Xerophthalmia codes (ICD-9 and WHO)</i></p> <p>normal = 1 night blindness = 2 conjunctival xerosis = 3 Bitot's spot = 4 corneal xerosis = 5 keratomalacia < 1/3 corn. surf. = 6 keratomalacia/cornea ulcer > 1/3 corn. surf. = 7 corneal scars = 8 N/A or missing data = 9</p>	<p>Eyes</p> <p>Ptosis <input type="checkbox"/></p> <p>Brushfield spots <input type="checkbox"/></p> <p>Cataract <input type="checkbox"/></p> <p>Retinitis <input type="checkbox"/></p> <p>Trachoma <input type="checkbox"/></p> <p>Squint <input type="checkbox"/></p> <p>Conjunctivitis <input type="checkbox"/></p> <p>Onchocerciasis <input type="checkbox"/></p> <p>Nystagmus <input type="checkbox"/></p> <p>Disks pale or atrophic <input type="checkbox"/></p> <p>Xerophthalmia</p> <p>Right eye <input type="checkbox"/></p> <p>Left eye <input type="checkbox"/></p>
<p><i>Thyroid: WHO Goitre Classification codes</i></p> <p>thyroid not palpable or, if palpable, not larger than normal = 1 thyroid distinctly palpable and definitely larger than normal but usually not visible when head is in normal or extended position = 2 thyroid easily palpable and visible when head is in extended position. Presence of a discrete nodule also qualifies one for inclusion in this grade = 3 thyroid easily visible with the head in a normal position = 4 goitre visible at a distance = 5 monstrous goiter = 6 unknown = 8</p>	<p>Ears</p> <p>Pneumatocopy</p> <p>normal=1 abnormal=2 not seen=8</p> <p>Otoscopy</p> <p>no=1 yes=2 uncertain=8</p> <p>Mouth</p> <p>Cleft palate <input type="checkbox"/></p> <p>Diminishing gag <input type="checkbox"/></p> <p>Missing, carious teeth <input type="checkbox"/></p> <p>Abnormal teeth <input type="checkbox"/></p> <p>Drooling <input type="checkbox"/></p> <p>Thyroid</p> <p>«Enter WHO Goitre Classification» <input type="checkbox"/></p> <p>Chest</p> <p>Rales <input type="checkbox"/></p> <p>Wheezing <input type="checkbox"/></p> <p>Cor</p> <p>Murmur <input type="checkbox"/></p> <p>Abdomen</p> <p>Distended <input type="checkbox"/></p> <p>Hepatomegaly <input type="checkbox"/></p> <p>Splenomegaly <input type="checkbox"/></p>

(Physical examination continued)

Genitalia

girls = 1

Large testicles

Undescended testicles

Spine

Kyphosis

Scoliosis

Spina bifida

Extremities: (arms, legs and feet)

all normal = 1 right arm = 2 left arm = 3
 both arms = 4 right leg/foot = 5 left leg/foot = 6
 both legs/feet = 7 one arm and one leg/foot = 8
 both arms and legs/feet = 9

Wasting

Abnormal

Angulation

Contractures

Absent

Atrophy

Hands

both normal = 1 right hand = 2

left hand = 3 both hands = 4

Absent

Partial absence

Digits extra (abnormal)

Short fingers

Fisting

Physician: In your opinion, did this constitute an adequate physical exam of the child?

yes = 1 no, child uncooperative = 2 no, not enough time = 3 not sure = 8

Does this child get a full neurological examination based on results from Observation of Function, Physical Examination or History?

no = 1 yes = 2

Additional comments on the physical exam:

Other abnormality not noted above (e.g. ichthyosis, etc.)

IV. Neurological exam: for all children who fail or score uncertain on the observation of function**Motor exam****Mobility**

normal gait = 1 not normal, but ambulant, no aids, independent = 2
 ambulant with aids, independent = 3 ambulant with aids, limited = 4
 not ambulant, wheelchair only, but independent = 5
 not ambulant, wheelchair only, limited = 6
 not ambulant, bed ridden or wheelchair = 7 uncertain = 8

Manual Dexterity (observed during the Observation of Function)

normal = 1 slight impairment = 2 moderate impairment = 3
 marked impairment = 4 no useful function = 5 unknown = 8

Right hand Left hand

Use codes no = 1 yes = 2 uncertain = 8 for the remaining questions in Part IV unless otherwise indicated

Is the child in a frogged position when lying down? When you pick the child up under the arms do his/her legs scissor?

code = 7 if child is too heavy to lift

Move each of the four limbs around the major joints (shoulders, elbows, wrists, hips, knees and ankles). Is any limb hypotonic?

Right arm Left arm Right leg Left leg

Is any limb hypertonic?

Right arm Left arm Right leg Left leg Do you notice any involuntary movements? Does the child seem unstable, ataxic or show titubation? Can the child sit unaided?

Tap out reflexes at biceps, knees and ankles. Are reflexes completely absent in:

Right arm Left arm Right leg Left leg

Do reflexes seem exaggerated in:

Right arm	<input type="checkbox"/>
Left arm	<input type="checkbox"/>
Right leg	<input type="checkbox"/>
Left leg	<input type="checkbox"/>

You have observed the child walk, stoop and stand up. Is there any evidence of:

proximal muscle weakness?	<input type="checkbox"/>
distal muscle weakness?	<input type="checkbox"/>

Sensory exam

Test sensory functions only if indicated by the nature of the motor exam; i.e. only if there are motor deficits in the distribution of a peripheral neuropathy, or a spinal level such as meningomyelocle.

If there is sensory loss?
 If so, describe: _____

Physician: In your opinion, was this an adequate neurological exam to assess this child?

yes = 1 no, child uncooperative = 2 no, time too short = 3 uncertain = 8

If cerebral palsy is diagnosed, enter the ICD-10 code here: G _____
 (See MAF Procedure Manual, Appendix B for coding)

Additional comments on the neurological exam:

V. Anthropometry, vision and hearing (complete for all children)

A. Physical measurements: required for all children

Child's height (cm):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Child's weight (kg):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Child's head circumference (cm):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Child's mid upper arm circumference (cm):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
* Mother's height (cm):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
* Mother's weight (kg):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
* Mother's head circumference (cm):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
* Mother's mid upper arm circumference (cm):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

* Optional for mothers — omit mother's if informant is not the mother.

Does the child's mother appear healthy?
 yes = 1 no, not quite healthy = 2 no, appears ill = 3
 uncertain = 8 d/k mother not present = 9

B. Vision and hearing evaluation: all children

Vision acuity: For 3-9 year olds who can follow C or E chart instructions use Landholt C chart if possible. Otherwise use E chart.

6/6 or better (20/20 or better) = 1 Right eye
 6/9 or better (20/30 or better) = 2 Left eye
 6/18 or better (20/70 or better) = 3
 6/60 or better (20/200 or better) = 4
 6/61 — light perception (20/201 thru light perception) = 5
 no light perception = 6
 untestable = 8

Vision acuity: For 2 year olds and older children who cannot follow C or E chart instructions, use "fix and follow" test. Right eye
 Left eye
 1/32 k = 1 1/8 k = 2 1/2 k = 3 6 k = 4 Failed all = 5
 N/A, used C or E = 7 untestable = 8

Hearing Right ear
 pass = 1 fail = 2 Left ear
 For 2 year old children use Downs test Overall
 For 3-9 year old children use audiometer

Was the audiometer used to screen this child's hearing
 no = N yes = Y

If yes, indicate the screening cutoff in dB for the particular site/day and whether the child passed or failed at each Hertz level given in the table below (enter 1 for pass and 2 for fail).

Screening cutoff		Hertz			
		500	1000	2000	4000
_____ dB	Right ear	_____	_____	_____	_____
	Left ear	_____	_____	_____	_____

Comments:

Please consider the known syndromes and diagnoses when filling out the diagnosis column of the summary sheet on the next page; such as Down Syndrome, Fragile X, Spina Bifida, Cerebral Palsy, Neurological Cretinism, Polio, Congenital Rubella, PKU, etc.

VI. Summary Sheet (complete for all children)

Examiner: For each type of problem listed below, indicate whether you think impairment is present or not. If impairment is present indicate the diagnosis and ICD-9 codes, the degree of disability (see MAF Procedure Manual for criteria) and whether or not the child has an unfulfilled need for treatment (including rehabilitation, medication or referral for further professional evaluation and/or therapy).

Type of impairment	Diagnosis	ICD-9 Code	Disability	Treatment needs
is there impairment? (circle No for no or probably no.	see MAF Procedure Manual	see MAF Procedure Manual	1=none 2=mild 3=moderate 4=severe 8=uncertain	1=none 2=CBR 3=professional eval. 4=medication 5 = 2 & 3; 6 = 2 & 4 7 = 2, 3 & 4; 8 = other
Gross Motor No Yes	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fine Motor No Yes	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hearing No Yes	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vision No Yes	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Speech No Yes	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Seizures No Yes	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cognition (physician only) No Yes	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychiatric No Yes	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nutritional No Yes	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other No Yes	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
* Cognition (joint decision) No Yes	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

* Joint decision regarding cognition refers to the rating given by the physician and psychologist jointly, after discussion. If this differs from the physician's earlier rating do not change the earlier one.

Summary comments:

APPENDIX D

REHABILITATION/REFERRAL FORM (RRF)

To be completed by the medical and/or psychological examiner(s)

Child's name _____

1. Brief summary of examination findings

2. For the disabilities or problems mentioned under (1) above, has the child received any rehabilitation, special training, or medical treatment? (Including previous and current, home-based and institution-based, traditional and modern treatments.)

Yes, adequate (1) Yes, but not adequate (2) No, none (3)

3. If not adequate or no to (2), why not? Check all that apply:

- no treatment/services available yes no
- too expensive yes no
- transportation problems yes no
- lack of free time yes no
- lack of interest yes no
- lack of knowledge of services yes no
- other (*explain*) yes no

4. If yes to (2), give the following information for each rehabilitation or treatment service received:

Type _____

Where obtained _____

Dates _____

Did the informant feel it was effective? _____

5. Does this child need any special help (rehabilitation or medical or psychological treatment)? yes no

If "yes" to question (5), answer questions (6-14) below.

6. Could the child benefit from community-based rehabilitation, such as the WHO manual *Training in the Community for People with Disabilities* and accompanying packets? yes no

7. If yes, specify an appropriate CBR plan for the child. yes no
8. Does the child need to be referred for professional or medical services? yes no
9. If the child does need professional services, specify one or more types of services required and where the child should go for each. yes no
10. Specify the person or persons who will be responsible for seeing that indicated interventions are carried out?

For items (11) through (14) indicate whether the statements apply (yes) or do not apply (no) to at least one of the child's parents or other primary caretakers

11. Seems to be aware of the child's special needs. Comment: yes no

12. Seems concerned that the child receives some kind of special help. Comment: yes no

13. Seems willing and able to cooperate with the rehabilitation or treatment plan indicated. Comment: yes no

14. Appears to have adequate financial resources, free time and social support needed to carry out the recommended rehabilitation or referral plans? Comments: yes no

APPENDIX E

**LIST OF FORMS USED IN THE
TWO-STAGE METHOD OF IDENTIFYING
CASES IN THE COMMUNITY**

1. Household Form
2. Mother-Child Form
3. Ten Questions
4. Child Disability Questionnaire (Revised, CDQ-22)
5. Adaptive Behaviour Scale
6. Diagnostic Decision Sheet
7. Medical Assessment Form
8. Rehabilitation and Referral Form
9. Community Description Form

SECTION III

THE USES AND ABUSES OF PSYCHOLOGICAL TESTS IN CHILDHOOD

There is a shortage of psychologists and other trained mental health personnel in developing countries. There is, however, no lack of mental health problems in the child population and non-mental health professional, aware of this fact, are increasingly eager to assess children who are slow to develop or backward in their education.

Opinions about the value of psychological tests vary — some believe they are indispensable to satisfactory assessment of many problems; others think they should never be used. The following text provides a discussion of their possible value. It is intended for professionals, such as teachers, child health doctors, psychiatrists, public health nurses — especially those working in developing countries — who have not had a training in clinical or educational psychology, but who wish to know more about the use of psychological tests in childhood.

A psychological test

A test is a way of helping find out something about a person, in this case, something about the way the person thinks, feels or behaves. For the purposes of this paper we confine ourselves mainly to tests of development, intelligence and success in school work.

Readers may object that they do not need a test to find out how well a child is doing at school; all they need to assess reading, for example, is a page or two from a book which the child has to read aloud. It is true that for some purposes this approach will be adequate but it has many drawbacks.

1. It is unsystematic. Three people might choose three different books.
2. It gives no indication whether children are reading to the level normally expected of children of their age and so no valid conclusion on whether or not they are doing as well as might be expected can be drawn.
3. It allows for wide variation in administration: one person might use a book with pictures

illustrating the story which will give the child some clues available only in that kind of book.

Similar objections can be made to a number of approaches to assessment. Before coming to any conclusion on their validity it is essential to have some understanding of different types of test, the different uses to which they can be put, some of the ways of using information gained from tests and some of the difficulties that arise in the interpretation of test results.

Types of test

There are several ways of classifying tests, according to the way they are constructed, according to the use to which they are put or according to the topic they are addressing.

Classification according to the construction of a test

1. *Standardized or non-standardized*

A *standardized test* is one that enables one child to be compared with others. The most common example of this is the intelligence test: when we examine the results we may place the children in order of measured intelligence.

There are three important aspects of the use of standardized tests:

- i) Age can be allowed for, a younger child may obtain a higher score than one who is older because he or she has done better allowing for the age difference.
- ii) The content of the test items should be relevant to the children taking the test.
- iii) The value of the results depends on how well the test has been standardized. The individual child's score is compared with those scores of children of a similar age who formed the standardization sample. For example, if in 1992 African children are given an American intelligence test standardized in 1960, the African

children's scores will be based on the performance of children in another country 32 years before.

There should therefore, be two major questions put before a standardized test is used:

- Is the content relevant to the children taking it ?
- Are the children being compared with a relevant sample ?

A *non-standardized test* is one in which the enquiry is about a specific skill rather than comparison with other children. In mathematics, for example, it may be helpful for a teacher to know whether children understand the four rules of addition, subtraction, multiplication and division. So we give tests using these four rules and examine the results. For our purposes it is not important if the child does better or worse than others; we are interested only in how well these four processes have been mastered.

This type of test is sometimes referred to as a *criterion referenced* measure, because the aim is to see if children reach certain criteria.

2. Individual or group tests

Individual tests are given to only one person at a time. They have many advantages:

- i) They allow for a wide range of answers so original thinkers will not be penalized for failing to respond in a conventional way.
- ii) They allow the examiner to make observations about the child's behaviour during the test.
- iii) They allow for a wide range of skills to be tested at one time.

On the other hand, they may take up to an hour and a half per child and thus may be too expensive in terms of time.

Group tests are much quicker and cheaper than individual tests but they cover a narrower range of topics and in a crowded room there is always the possibility that children will copy from each other.

Classification according to the uses to which tests can be put

1. Assessment of development

Whether or not young children are delayed, it is valuable to appreciate the pace at which devel-

opment is occurring. If the attention of parents is drawn to the ways in which a child is developing, they will often become interested in providing the best opportunities they can to stimulate the child appropriately.

If the child is delayed in development, this may be because:

- i) The quality of care provided has been poor.
- ii) The child has a physical problem affecting brain function. This may, for example, be an inherited disease, an abnormality of the chromosomes, an infection in pregnancy, birth injury, poor nutrition, an illness after birth such as meningitis, or a head injury, but there are a number of other causes.
- iii) Often development is delayed because of a variety of physical causes and poor care.

In these cases there are special reasons for monitoring development regularly. The results of assessment can lead to parents and others realizing the need for extra stimulation, or, more rarely, for less stimulation. In addition, if gross delay occurs, the parents and others can then be helped gradually to alter their expectation of the child's future performance and to plan for the child's future schooling in a realistic way.

2. Assessment of a learning problem

The most common use of tests at the present time in developed countries is in the assessment of children who are having difficulties in learning at school. Tests can be helpful in helping teachers and parents to find out what is wrong and to make a plan for remediation.

A test of general intelligence can be combined with attainment tests to give an idea of the child's strengths and weaknesses. It can indicate the level at which the child is achieving in relation to children of his own age. The way the child tackles a test can provide information of his attitude to learning in general and to tasks he finds difficult in particular. It can provide clues to those remedial approaches which are likely to be most successful. Thus, if a child is strong in some components of learning but weak in others, a teacher may be able to work out ways in which the child can either bypass the weak areas or have extra practice in them. Finally, the results of testing may assist decisions regarding the type of education likely to be most suitable for a child. For example, if special education is

available, test results may help to indicate whether such schooling may be appropriate.

3. *Screening and surveillance of a child population to identify children with problems or potential problems*

If extra resources for dealing with children with problems are available (and it must be said immediately that in most developing countries at the present time they are not), it is obviously desirable for those children most in need to receive them. If reliance is placed on such children being brought for attention by their parents, many will be missed. For this reason, screening programmes have been devised in many developing countries to identify children with delays in development and learning ability as well as disorders of movement and sensory deficits such as poor sight or hearing.

In young children screening has to be carried out on an individual basis. Once children reach the age of seven or eight years it is possible to use group screening procedures. Thus a class of children can be given a reading test simultaneously. The general standard of reading ability in a class can be readily appraised and those children with reading difficulties can be identified. These can then be individually assessed so that appropriate remedial measures can be taken. Screening of this type when carried out with both preschool and school-age children can also be seen to have a preventive function.

In recent years the practice of screening on a one-off basis has been heavily criticized since it is generally a crude approach. In its place has come the practice of surveillance, in which children are monitored over a period of time. The tests used as screening instruments can be a valuable part of this process.

4. *Research*

Psychological tests have widespread use in scientific investigation. They can be used on their own in some studies, for example:

- To measure the effects of a literacy programme.
- To investigate the prevalence of mental retardation in a country or a district.

They can also be used in more sophisticated studies assessing the relative merits of alternative types of intervention. For example, it is known that malnourished children are behind those who are well nourished in several ways. If

a programme of help for malnourished children is instigated using food supplements, plus increased educational provision for the children and possibly the parents, plus a campaign to reduce the birth rate, psychological tests can be used to help tease out the relative contribution of each aspect of this programme.

Classification according to the topics addressed by tests

1. *Development in children up to the age of 3 or 4*

These tests are nearly always individually administered but they could be adapted so that surveys based on mothers' reports could be carried out. Some look only at specific areas of functioning, for example, language development. Others consider a wider range which include visuo-motor and locomotor skills and social behaviour as well as language.

2. *Intelligence*

Tests in this category involve many tasks, examples being tests of reasoning using both words and objects, drawing ability and memory. Individually administered tests usually include some measures of the child's speed of work.

3. *Attainment in school*

Reading, spelling and mathematics are the most common tests in this category.

4. *Other specific areas of functioning*

As well as being included in the tests noted above, the following areas of functioning have had tests devised for use with children:

Attention	Fine Motor Skills
Language	Memory
Visual and Auditory Perception	Visuo-Motor Skills

5. *Behaviour*

Scales to measure behaviour have been devised in which teachers or parents note whether certain behaviours occur in a child. These scales can give a general picture or they can yield information on specific areas, overactivity being an example.

For a fuller discussion of what is obtained from the above tests, see the section on the interpretation of test results below.

The interpretation of tests results

Objective tests can be used to assess a number of aspects of an individual's functioning. Some of these aspects overlap and cannot easily be distinguished from each other. All the same, rough guides may be helpful.

1. Development

Young children vary in the rate at which they acquire skills such as language, the ability to handle objects, the capacity to recognize and make relationships with other people. Developmental tests assess the level of development which a child has reached at a particular point in time.

In thinking about developmental tests, it is important to bear in mind the following:-

- i) Many children develop unevenly, some skills being in advance of others. It is often important when describing the results of a developmental test to make this clear. Thus one may say that a child is at a two year level in the expression of language, but only at an 18-month level in the understanding of language. If a child's level of development is even, then it may be useful to describe this development in terms of a global score — for example "the child is functioning at a 20 month level". However, if there is unevenness, then a global score will be misleading.
- ii) For most children the level of development in the first five or six years of life is only slightly related to their later intellectual level. Many children who develop slowly in the first few years of life are of normal ability later. All the same, a child who is *very* slow to develop early on — for example who is amongst the slowest 3 in every hundred in the population — is a cause for concern and does have a high risk of showing learning problems later in life.
- iii) Even in the first few years of life, levels of development may vary depending on the cultural group to which an individual belongs.

2. Intelligence

Individuals vary in their general intellectual ability, their capacity to reason logically, to work out how to do things with their hands and so on. The differences between individuals in their intelligence is produced both by differences in

genetic make-up and by variation in upbringing or environment. Intelligence (IQ) tests assess intellectual capacity at one point in time, and of course this is likely to vary as time goes by.

One important way of thinking about intelligence is to see it as the ability to adapt to and master the environment in which one lives. Different skills and abilities are required to adapt to and master different environments. If a society does not use a written form of language, the ability to read is not relevant to adaptation. Vocabulary is to some degree determined by a society's needs. For example, the words it is important to know will vary depending on whether it is customary to discriminate between ten different kinds of snow or ten different makes of motor car. The visual ability and motor co-ordination required by a member of a fishing village to detect and catch a shoal of fish will be different from the visual and motor ability required to avoid a traffic accident in a busy city street. If one of the purposes of tests of intelligence is to measure an individual's capacity to adapt to his environment, the tests will need to be different if the environments are different.

Most intelligence tests have been devised by psychologists working in cities in developed countries. It is not surprising that these tests are most suitable for assessing the adaptive abilities of children living in the same settings; such tests are often less suitable, or even totally unsuitable, for children living in quite different circumstances, for example in rural areas in developing countries.

Most tests of intelligence assess a wide range of skills, some of which are concerned with language — vocabulary, ability to express and understand. Others are concerned with abilities such as memory, visual perception, symbolic thought and motor skills. The intelligence quotient may be expressed as a total score, or as a verbal and non-verbal score or each function tested may be given a separate score. Usually the score obtained on the tests are recalculated in such a way that the mean score of the test is 100.

In considering the results of intelligence testing it is important to bear in mind the following:

- i) It is sometimes said that intelligence tests measure a child's inherent or inherited ability. Of course, one of the factors contributing to the child's intelligence will be inherited potential for intellectual development and learning. But the child's experience and opportunities for learning in

- the past are also important factors determining intelligence test scores.
- ii) It is sometimes said that intelligence tests measure a child's "potential" ability. This makes it sound as though they can assess what the child has inside which will automatically unfold in the future. It is true that intelligence test results are often constant over time. But this may be as much because the child's environment provides a fairly constant or consistent quality of stimulating experience, as to the fact that the child's ability unfolds at a constant rate.
 - iii) Intelligence tests' scores often vary quite widely over time. Changes which occur over a few months may be due to disease factors such as some disorders of the brain. They are however much more likely to be due to changes in the child's attitude to testing, or to a different tester using slightly different methods, or to a normal variation in the child's pace of development, or to the fact that the test happens to measure slightly different functions at the two points in time when it has been administered.
 - iv) One should not assume that a child with good verbal skills will also do well with tasks involving visuo-motor abilities like jig-saw puzzles or matching patterns. Nor is one who is poor at the latter generally backward. A good test will look at both aspects.

3. Attainment

When children do badly in school there are a number of possible reasons to explain their problems. It is always worthwhile investigating a range of explanations since it is otherwise easy to label children as dull. One of the arguments for using intelligence tests of some kind is to avoid falling into that trap.

In general the attainments of children are likely to be more or less at a similar level to their intelligence. Thus, if a ten year old child is performing on intelligence tests at an eight year level, then it is likely that his or her reading ability will also be around that of an eight year. However, sometimes results of intelligence and attainment tests vary widely. Possible explanations for this include:

- i) There may be an undetected hearing or visual loss.
- ii) Teaching may have been of poor quality or there may have been frequent changes in school.
- iii) There may be a specific defect unrelated to general intelligence, which is preventing learning. For example, children who find it difficult to deal with ordered sequences or who cannot easily tell right from left often find reading harder than others.
- iv) Anxiety or some other emotional disturbance may be getting in the way of learning.
- v) Factors like unusual levels of motivation, persistence and concentration may mean that some children do quite a bit better or quite a bit worse on tests of attainment than they do on intelligence tests.

4. Specific abilities

Tests of general intelligence involve assessment of a large number of different abilities. Some tests are designed to look in depth at specific abilities and impairments. These may, for example, assess the child's visual perception, memory, or motor co-ordination. In general such tests are likely to be of value only when employed by experienced and specialized psychologists and they will not be further discussed here.

Some common problems in the use of tests

If a person interpreting the results of a test has a clear idea of the reasons for carrying out the test in the first place, and is familiar with the way the test is administered and scored, it is unlikely that the results will be misinterpreted. Problems will however arise when:

1. An inappropriate test is used. The test is inappropriate if:
 - i) It has not been designed and tested on members of the population from which the child is drawn (see also the section on standardization above).
 - ii) The child cannot understand the test instructions properly because of unfamiliarity with the language of the test.
 - iii) The child's age is outside that for which the test was developed.
 - iv) The functions the test measures are not those the tester really wishes to assess. For example, if one wishes to have an idea of the child's general ability but uses a test

not involving language, only a partial view of the child's intelligence will be obtained.

2. The person administering the test does not follow the rules laid down in the manual. Most tests devised for administration by psychologists have rules laid down for administration and scoring. If these are not strictly followed, the results obtained will not be comparable to those obtained from children on whom the test was standardized.
3. The person administering the test has an accent or manner unfamiliar to the child.
4. There is inadequate communication between the person administering the test and the person needing to know the result. When for example, psychologists administer tests and teachers or doctors have to use the results, it is important that there is direct and meaningful contact between one and the other.
5. Incorrect conclusions are drawn from the results of the test. The most commonly drawn *wrong* conclusions are:
 - i) *"A child with a very low score will never improve and is not worth teaching."* On the contrary, unless the child has a progressive brain disease, given the right opportunities there will be progress even if it may sometimes be very slow.
 - ii) *"An intelligence test result provides a good indication of the way children will function throughout childhood and adolescence."* This is a dangerous belief and can result in children being wrongly labelled. It is true that if tests are applied at two points in time to a large group of children over the age of six or so there will be quite good agreement between the results on the two occasions. But the scores of a number of individuals will differ widely. A child who is functioning poorly at five years may be in the average range at ten years.

Adaptation of existing tests for local use

When considering the need for a test, it is obviously more tempting to adapt an already existing test than to embark on the development of an entirely new one. For this reason, many workers

in developing countries have translated existing tests and applied them more or less unchanged to a local population. There are dangers to this approach. In particular:

- i) Some items will not be understood, for example, questions about beer and wine in a society which forbids alcohol.
- ii) Some items, for example questions about a telephone, will not be relevant. It is essential sometimes to consider the different experiences of children within one country, for example those in urban and rural settings.
- iii) It should not be imagined that non-verbal tests are culture fair. Many Western tests depend on children drawing, interpreting and manipulating shapes and pictures. It is by no means certain that any tests based on these types of material will be applicable in cultures other than those for which they were devised.
- iv) It will not be possible to interpret the results of the tests if only the original standardization data are available. It cannot be assumed that children from outside Britain, who score at the 50th percentile according to British norms, is of average ability.

For these reasons, the use of Western tests in developing countries, or, for that matter, on immigrant children in developed countries, has been strongly and correctly criticized. Nevertheless, apparently successful adaptations have been made. In undertaking adaptations of existing tests, the following principles need to be observed:

- i) The assistance of a psychologist experienced in test construction or development is essential through the procedure. This might be achieved by a relatively short-term consultancy.
- ii) The test should initially be translated by someone familiar with both languages.
- iii) The test should then be independently translated back into the original language by another interpreter. Language problems thus revealed should be settled by discussion and items for which no adequate translation exists should be eliminated.
- iv) Items containing material or concepts unfamiliar in the culture should be elimi-

- nated and possibly replaced by similar relevant items.
- v) The test should then be piloted on a group of children drawn from those on whom it is proposed to use the test. Items should be modified on the basis of this experience.
 - vi) An item analysis (see Glossary) should be carried out to eliminate items which do not discriminate at certain age levels.
 - vii) Finally, the test should be applied to a large number of children representative of the population in which it is proposed to use the test. The testing of a representative sample is an exercise expensive in time, but it can be carried out by trained volunteers such as university students. Teachers often find testing very difficult because their training has taught them to help children who cannot understand a task, and it is important, in the development or use of a test, that children are not given help.

The sample should be representative for sex, geographical location and social class, and there should be a sizeable number of children at each age. If the test is for school-age children and not all children in the population attend school, it may be better to develop two parallel versions. It may also be helpful to develop parallel tests for urban and rural children.

Once the task is completed it will provide an invaluable source of comparison. Further, the standardization procedure will itself provide helpful information on age trends, sex and social class differences in the population.

Developing a new test

In considering the development of a new test the following matters will need to be considered:

- i) What is the purpose of the test? For example, is it to identify the different abilities of children across the whole range, or would it be sufficient to be able to identify those with a severe problem? Most tests from developed countries are related to success in school. This may be appropriate but it may not be. Some enquiry into local definitions of ability or intelligence may be fruitful.
 - ii) What ages is it intended the test should cover?
 - iii) How can the population on which the test is to be used be defined? In particular, what are the language characteristics of the population? Are these reasonably homogenous?
- In developing a new test, once again the skills of a psychologist experienced in such procedures is necessary, although much of the field testing can be carried out by less skilled volunteers such as university students.
- Attention needs first to be given to devising items for use in the test. Almost certainly an examination of items from already existing tests will be rewarding. However, knowledge of local values and attitudes to skills may well result in the development of entirely new items. For example, knowledge of kinship patterns of little relevance in most developed countries might be of considerable adaptive value in some societies. Other examples of local values could be obtained from observations of children's play, from craft or hunting skills, from religious practice and social conventions.
- It is important that the test items discriminate between children of different ability. There is no substitute for trying out items on readily available groups of children of different ages in order to arrive at appropriate levels of difficulty.
- Having established, on the basis of pilot studies, a range of tests for each group, it is then necessary to produce standardized instructions and standardized material for the administration of each individual item. The amount of time allowed, the degree of encouragement and help permitted, the point at which testing on an item is discontinued because of repeated failures — all these matters need precise instructions, as well as the actual details of the presentation of material and instructions given to the testee. When new problems arise, those developing the test should record them, work out procedures for dealing with them and then ensure that appropriate instructions are entered into the test manual.
- Norms for the standardized test should then be obtained on a representative sample of the population on which the test is to be used. A brief description of the techniques involved in this procedure is described in the previous section.

The use of tests in different settings and by different people

The health clinic and the village health worker

1. The general population of children

Staff in health clinics see a preponderance of young children, a proportion of whom will have developmental delays of significance for later progress, a number of whom will be quite severely disabled. Further, in many societies, parents are uncertain whether their offspring are developing normally, and they may require reassurance. The availability of simple materials testing infant and preschool development will enable all these functions to be served more easily.

In some developed countries, screening for the purposes of identification of delayed or deviant development is undertaken routinely at set ages. An attempt is made to assess all children four or five times before school age. This procedure is expensive and cannot be recommended as a service of high priority in developing countries where professional resources are scarce. Nevertheless, if the opportunity is taken to assess the development of children who attend for health reasons, and if the progress of the child is discussed with the mother, in many parts of the world a substantial proportion of the child population would be covered. In this context several countries have added records of developmental milestones to children's health record cards, thus facilitating communication between the health care worker and the mother about psychological development.

2. Children with problems

Some children will attend health clinics because their parents are worried about their developmental progress. Others will attend for physical complaints which turn out to be related to learning problems. For example, children with stomach-aches, headaches or other functional complaints may turn out to be children of generally low ability of whom too much is expected either at school or in the home. Specific learning impairments may present in the same way.

Staff in the health clinic will not, in general have the facilities to carry out a full appraisal of such learning problems, nor will it be appropriate for them to do so. But they should have techniques and materials available which will allow them to make a rough estimate of the child's ability and attainment. This will enable

them to talk sensibly to the mother about the learning problem, so that she may then be able to talk with the teacher and between them teacher and parent can work out the best approach to the child's learning problems.

The school and the teacher

1. *Screening tests* can be used by teachers to identify those who are likely to have severe learning problems. It is vital to identify such children as early as possible for these reasons:

- i) They can be given a full medical check in case there is a remediable condition.
- ii) Expectations of the child's performance can become as realistic as possible.
- iii) Appropriate education should be provided.

Such tests can also identify children with mild learning problems although they are less accurate in this field than with the severely disabled child. If remedial help is available, then it is worthwhile trying to identify this group.

Screening by teachers should always be carried out with the aim of helping the child; in most cases this means that unless the child has a remediable physical disability, teaching methods will have to be changed to some extent as a result of the observations made.

2. *Attainment tests* may be used once the child has started to learn formally. In most schools they are confined to reading, spelling and mathematics and they can be given to a group of children or individually. Their purpose is to give some measure of how well the child, or class, has progressed in a certain area, and results are generally expressed as a Reading Age, Spelling Age, or Mathematics Age. Because those tests may have been standardized on a group of children quite different from those on which it is being used, it may be wise to ignore the concept of the Attainment Age and to use the test results as a way of monitoring progress. However they are used teachers should not be misled by the apparent simplicity of attainment tests; advice from someone experienced in their administration and interpretations will always be helpful.

3. *Diagnostic tests* are used to investigate any weaknesses which are thought to be underlying

ing any failure to make progress in a certain subject and are almost always given individually and fall into three categories:

- i) Those related to basic skills assumed to underlie learning. For example, children who have reading difficulty may find it hard to discriminate between similar sounds. Problems in mathematics may be traced to a failure to understand the language involved ("large", "small", "multiply" and "divide" are early examples). Most work has been done in skills assumed to be related to reading and although this is an attractive approach few tests have gained general acceptance.
- ii) Detailed tests of the skill itself. In reading it is often more helpful to use a test which uses letters and words.
- iii) Assessments of learning style. Some teachers set up a small experiment in class to observe a child's approach to learning. It may be found, for example, that one child always tries to finish the work as quickly as possible at the expense of accuracy. Another may pick on part of the question instead of working to the whole. This is not a test in the normally used sense of the word, it is an assessment technique.

Health and education monitoring and research

i) Surveys.

The use of standardized tests will be indicated where it is intended to carry out surveys of the child population. For example, if a government department wishes to assess the level of literacy in the population, it will be necessary to use a standardized reading test on a sample of children of a particular age. A study of the prevalence of mental retardation would require the use of standardized methods of identification.

ii) Specific studies of psychological functioning.

Investigations in which links between physical and mental functioning are examined will require the use of some form of standardized psychological assessment. Thus, for example, investigating the relationship between intellectual level and the state of nutrition in the early years of life, or between intellectual level and the introduction of a nutrition programme will require the use of appropriate tests.

Intelligence

There is no generally accepted definition of intelligence. The Oxford Dictionary gives "intellect, understanding" and also defines intellect as "faculty of knowing and reasoning".

Other definitions include; the ability to perceive relationships; the ability to adapt to the environment; the ability to carry out abstract thinking; the ability to act purposefully, to think rationally and to deal effectively with the environment.

Standardization

After trial runs and item analysis the final version of the test is given to a sample of children, often to several thousand, chosen to be representative of variables thought to have a bearing on performance in the area tested. It is customary to sample by age, sex, social class and geographical location as a minimum. This sample provides the normal or average achievement against which an individual child may be compared.

Item analysis

Each item of a test is given a difficulty rating by establishing the percentage of children getting it right. It is then possible:

- a) to manipulate the level of difficulty of the test as a whole by selection of items for certain age groups according to their difficulty rating.
- b) to rank items with those most commonly passed at the top and those least commonly passed at the bottom, thus establishing which questions are most effective in discriminating between the children.

Raw Scores

The actual marks obtained on a test. For criterion referenced tests these are all that are required. For norm referenced tests they have to be converted to percentiles or standard scores.

Percentiles

All scores from the sample used for standardization, are arranged in order of merit and fitted to ranks 0 to 100. The highest score is then at the 100th percentile, that halfway at the 50th. A child who is better than three-quarters of the group will be at or above the 76th percentile.

Standard scores

These are based on the normal distribution curve and the standard deviation. Many tests use a standard deviation of about 15, and a mean of 100 so a score of 130 indicates that the child is two standard deviations above the mean.

Standard deviation

This is a measure of how widely scattered the individual scores are.

The normal distribution curve

Many attributes, e.g. height, are normally distributed, that is most people are within the average range with a few at the extremes.

standard scores

55	70	85	100	115	130	145
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standard deviations

-3	-2	-1	0	+1	+2	+3
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cumulative percentages

.1	2.3	15.9	50	84.1	97.7	99.9
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The Intelligence Quotient is a figure usually based on a mean of 100 and an S.D. of 15 or 16.

Reliability

This is a term referring to the consistency of a test. It can be measured by retesting the same child (test-retest), by two testers marking the same test performance (inter-tester reliability), or by examining the degree to which a child's performance on one half of the test agrees with the performance on the other half (split-half

reliability). Reliability is normally expressed as a coefficient; a minimum expected for tests of the sort described here is 0.8.

Validity

This term refers to the accuracy with which the test does what it aims to do. So a language test should be able to pick out children who are truly exceptionally good, or poor in that area. Validity can be predictive, that is, it is able to identify children who are shown later to have the attributes identified by the test, or concurrent, that is the test describes children in a way that agrees with an accepted criterion. An example of concurrent validity is found when a test can discriminate between groups of children already known to differ along the relevant dimension.

N.B. Tests can be highly reliable without being valid.

Sample

In statistical terminology a sample is a group of observations. As far as possible the sample should be representative of the population from which

it is drawn. Adequate sampling usually entails ensuring that the sample contains subjects in the same ratio on certain variable as are found in the population. The minimum variations are usually; sex, age, ethnic origin, social class, inner city/outer city/rural dwelling. In developing countries other variables such as religion may have to be taken into account.

Standard error of measurement

The standard error allows one to predict the range of scores likely to have occurred by chance. It is expressed in terms of confidence limits.

Thus for a WISC-R Full Scale IQ score of 100 at age 10, the SEM indicates that there are 95 chances out of a 100 that the "true" score is between 94 and 106. While this level of sophistication is unlikely to be of everyday need, it helps to realize that even the best tests, administered in the most accurate way, give results which have some built in variability. No test is perfect.