

**FINAL REPORT OF THE RESEARCH PROJECT
RAPID EPIDEMIOLOGICAL ASSESSMENT OF CHILDHOOD
DISABILITY IN PAKISTAN**

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I. INTRODUCTION:

Despite the growing awareness of disability worldwide (Hammerman 1981), in developing countries disabilities have not received the priority they deserve. In part, this is because most developing countries are still struggling to provide basic health care and reduce mortality. Children in developing countries are the ones to suffer most from the strong and pervasive grip of such common malaise as severe protein calorie malnutrition, diarrhoea, and measles and other acute infections. In many countries such conditions claim the lives of one fifth or more of children under five years (Rhode et, al., 1978, WHO 1989) and no doubt leave many more disabled. In allocating the scarce resources available for public services in developing countries, policy makers usually give low priority to health, while disabilities such as mental retardation are never even considered a policy issue. The official “invisibility” of childhood disability in developing countries does not decrease its social consequences (Strein 1981). Childhood disabilities have enormous impacts – on the lives of children, on the emotional and financial well-being of families, and on society as a whole.

The low priority and lack of services for prevention and remediation of childhood disability may be due as much to lack of data and awareness as to paucity of resources. Basic epidemiologic data on prevalence and distribution of disabilities are needed before provisions can be made for prevention and care within a country’s overall public health and social service plans.

Impediments in carrying out epidemiologic studies of disability in developing countries are many. The scarcity of trained professionals and virtual absence of medical and educational records result in no readily available means of identifying cases of childhood disability. High rates of illiteracy add to the difficulties. Therefore, appropriate methods of case identification need to be developed.

To be useful, a method of case identification must be inexpensive, simple, rapid, (because of the large numbers of childhood to be screened or evaluated), and reasonably accurate. These requirements are difficult to satisfy by any one method. Studies of census data indicate that the use of a single question asking whether anyone in the household is disabled both misses disabilities like mental retardation that are not highly visible, and differentially under - enumerates disabilities in women and children (Chamie 1986).

Another low cost method that has been tried 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 informants (Belmont 1984; Thorburn, et al 1989). Again, children with disabilities that are not physically obvious are most likely to be overlooked by the informants.

Any alternative approach involves two phases: I. Door-to-door visits by community workers, to identify possibly disabled children, on the basis of the screen; and II. Follow-up assessments of selected children by professionals or semi-professionals. This is the approach taken in the Rapid Epidemiologic Assessment of Childhood Disability Project reported here. It has the most to offer to researchers and service providers working in less developed countries because it relies heavily on resources that are locally available in those countries;

namely, non-professional community workers. Professionals resources are used with maximum efficiency, since only samples of children (most of whom are screened positive are referred to phase II.

Pilot studies carried out in Pakistan and several other countries in 1980 and 1981 suggested that the Ten Questions provides a sensitive screen for severe mental retardation in 2 to 9 year old children, but that it generates excess false positives (Belmont 1986). In response to this observation, probe questions have been added to the Ten Questions. The version of the Ten Questions tested in the Rapid Epidemiologic Assessment of Childhood Disability studies includes these probe question is to be asked only if a problem is reported in response to the main question which it follows.

The original Ten Questions has also been modified to test whether the instrument could be used to screen for disabilities in children as young as 2 years. For this purpose an alternative version of Question 9 on speech is asked if the child is 2years of age.

The pilot studies of the Ten Questions, though informative, were limited in three respects: (i) the number of children screened per country was only about 1000 (which, for relatively rare disorders, is too small to test the validity of the screen or to provide stable estimates of prevalence); (ii) the professional evaluation procedures (which provided the criterion for validating the screen) may not have been sufficiently thorough or standard from child to child; and (iii) very limited data on potential risk factors for childhood disability were collected. The collaborative studies in Pakistan, Bangladesh, Jamaica aimed to overcome each of these limitations. In each country, more than 5,000 children were screened (6,365 in Pakistan); through and standard psychological and medical assessment procedures were employed in all three countries; and an attempt was made to collect data on a variety of potential risk factors for childhood disability. Another advance in the current study over previous work was the on-sits use of micro-computers and data management software in all three countries to facilitate more rapid and accurate data processing as well as local dissemination of the results.

II. PURPOSES OF THE STUDY:

The main purposes of this Epidemiologic study of Childhood Disability in Pakistan are:

- (1). To evaluate the reliability of the TQP and other instruments used in the study in terms of test-retest reliability.
- (2). To assess the validity of the Ten Questions in Karachi in terms of its sensitivity, specificity, and predictive value for detecting serious childhood disabilities in 2 to 9 year-old.
- (3). To determine the effectiveness of the probe questions in reducing the occurrence of false positive Ten Questions results;
- (4). To develop measures of potential risk factors for childhood disability that might serve as targets for prevention; and

- (5). To estimate the prevalence of childhood disability in 2 to 9 year-old children in Karachi.

III. Method and Procedures:

SAMPLING

A large sample was necessary to obtain reasonably stable estimates of prevalence and measures of validity. A cluster sampling strategy with probability proportionate to the size was employed. The probability of a cluster being chosen, was proportional to the estimated size of the population in that cluster (Kish 1965). With limited time and resources this methodology is less cumbersome than random sampling. Since one of the aims of the study was to estimate the prevalence of childhood disability in greater Karachi, an existing sampling frame for Karachi was sought. One devised by the Applied Economics Research Center (AERC) of Karachi University was found appropriate for this purpose. AERC used the 241 master plan development zones (MPD) of the Karachi Development Authority, and aggregated them into 59 larger zones, termed Analysis Zones (AZ). The basis of this aggregation was either matching of census tract boundaries with AZ boundaries, or the homogeneity of various MPD zones regarding socio-economic factors. Through a land use survey of 1955 and population estimation techniques, AERC had available information on the population distribution, housing patterns, and topologies of each of the 59 AZs.

Using the AZ Population estimates for 1987, the population of Greater Karachi is estimated to be 7,642,695 (Table 1). Nearly 6% of this population is considered rural and concentrated in 16 of the 59 AZs. To draw a sample of several thousand children, a plan was to select randomly but with probability proportionate to population size 9 of the 43 primarily urban AZs and 3 of the 16 primarily rural AZs. The 12 zones thus selected are scattered throughout the Greater Karachi Municipal Area. Within each of the 12 zones, a randomly selected block of contiguous households was selected for inclusion in the survey. For the first urban 6 zones included 350 households were included in the survey. For the remaining 6 zones, it was necessary to reduce this number because of time constraints. Table 2 gives the actual numbers of households included in the survey in each zone.

PHASE I. THE HOUSE-TO-HOUSE SURVEY AND SCREENING:

In each cluster, the field supervisor, made contact with the councilors and community leaders to acquaint himself with the socio-graphic features of the community. To ensure cooperation, it was important that contact be established with community leaders and elders before approaching the households. All households with 2-9 year old children were surveyed. This work was carried out by a team of five field workers (interviewers).

These university interviewers were responsible for the completion of Household Forms (HF, 1 per household, Appendix A), the Mother Child Forms (MC, 1 per mother with 2 to 9 year-old in the household, Appendix B), TQPS (1 per study child between the ages of 2 and 9 years, inclusive, Appendix C).

HF.

This forms obtain information on socio-demographic aspects including educational level and occupation of the head of the household, living conditions such as number of the rooms in the house, availability of water, and toilet facilities, fuel used for cooking and composition of the household and whether it consisted of a nuclear family (parents and one generation of children), an extended

family (one nuclear family plus other relatives), or a joint family (two or more nuclear families). Information was also included on the ethnic background of the family.

MC.

This was the second form administered by the interviewers and contains questions mainly about the mother, her education, occupation and whether she works outside the home, hours of work, age, age at birth of her 1st child, and history of pregnancies and births. A MC was completed for each mother of 2-9 year-old children living present at the time of the interview.

TQP

Each child if in the age group of 2-9 years had a TQP completed for him or her in the context of an interview with the mother or other guardian of the child. The TQP is described above. In addition to the Ten Questions and Probes, there is question at the end of the form asking whether the child had any other health problem. The TQP also contains a code indicating whether the child will be called for detailed evaluation in phase II. Every eighth TQP was marked with an X at the bottom of the last page to indicate that the child with that form, should be included in the random sample and evaluated in phase II regardless of the screening result.

These three survey forms (HF, MC, TQP) were given household numbers in advance; the field workers entered the mother number on the MC and TQP, and the child number to the TQP. These constituted the identification numbers and were entered in a register by the field workers on their return to the field center. Each survey form was printed on a different color for ease of collating. All the children screened positive as well as those to (irrespective of the screening outcome) called for detailed evaluation.

The length of time required to finish the interview in each household varied: one TQP about 15 minutes; the time for each additional TQP was about 5 minutes.

PHASE II. THE CLINICAL EVALUATION:

All children who screened positive and some of those who screened negative were child for the second phase, which consisted of a detailed psychological and medical evaluation. This evaluation serves as the criterion against which the TQP is evaluated. Therefore, standard procedures for the assessments and criteria for judging the severity of disability were used (these were developed in collaboration with the other members of the International Epidemiologic Studies of Childhood Disability research team). It is hoped that these procedures has ensured consistency in the evaluations from child to child as well as from country to country.

The detailed clinical evaluations were carried out at field centers established in each zone. It was found that in order to complete these evaluations, it was necessary to do them within two days of the household interviews. Generally, the clinical evaluation of a child was done on the day following the administration of the TQP. The teams conducting the evaluation consisted of four psychologists, two physicians and an assistant health worker. The psychological assessment required two hours or more per child; the medical assessment generally required an additional half hour.

Psychological Evaluation:

Psychological evaluation was carried out in detail. For most children, the cognitive assessment is based on 1985 Stanford-Binet performance test items. These items were selected in consultation with the Dr. Lillian Belmont and two authors of the Stanford-Binet 1985 revision, Drs. Thorndike and Hagen. Several other suggestions for the procedures were made and were incorporated after a pilot study. In Pakistan a verbal subtest was also included (comprehension) in addition to the five non-verbal sub-tests suggested for the present study (pattern analysis, copying, quantitative, bead memory, and memory for digits). For children too young to be tested with the Stanford-Binet (ages 3 and under as well as older children who were felt to be incapable of being tested with the Stanford-Binet), the Denver Development Screening Test (DDST) was administered.

Along with the Stanford-Binet or DDST, all children were evaluated using an Adaptive Behavior Scale. This Scale was developed by this team specifically for this study in order to assess the adaptive behavior of children in Pakistan. This test had items reflecting social competence. The areas covered by the Adaptive Behavior Scale are motor development, socialization, communication, self help, feeding, toileting and dressing. Information for this assessment is obtained from the mother or other caretaker as well as from the performance of the child.

A final component of the psychological evaluation was the administration of a revised version of the Child Disability Questionnaire, (CDQ), (Appendix D). the scoring of this test was modified from that used during the pilot study.

Two psychologists administered the selected subtests of the Stanford-Binet and the DDST while the other two administered the Adaptive Behavior Scale, and the revised version of the Child Disability Questionnaire (CDQ). Thus, each child was evaluated by two psychologists; one administering the Binet or DDST and the other administering the Adaptive Behavior Scale and CDQ.

The decision whether the child was normal or retarded and the degree of retardation was made based on these tests well as discussions among the psychologists who had administered different tests. This constituted the psychologists' assessment of cognitive impairment and disability. A separate assessment of cognitive impairment and disability was made by the physician during medical evaluation. Finally, a joint assessment of cognition was made by the psychologists and physician. In assessing cognitive disability, the categories 'normal', 'mildly retarded', 'moderately retarded', and 'severely retarded', were used. The 'physician' only and the joint decision regarding the diagnosis of mental retardation were recorded separately on the last page of the Medical Assessment Form (MAF, Appendix E).

Collecting Normative Data for the Psychological Tests:

Once the revision of the psychological instruments was completed, normative data were collected on a sample of about 300 children (following recommendations of Drs. Belmont and Hagen). A sample of 2-9 years old children was drawn for establishing norms for the Adaptive Behavior Scale, the Stanford-Binet and the DDST with representation of children from urban and rural areas (within urban areas both poor and middle class population were represented, while no socioeconomic distinction was made in the rural sample). Collection of the normative data on all the three tests was completed by September 1987.

The Medical Evaluation:

Complete medical evaluations were carried out by the physicians, while anthropometry, vision and hearing tests were done by the assistant health worker. The Medical Assessment Form (MAF Appendix E) and procedure manual (Appendix F) were used for these evaluations.

The medical evaluation starts with questions on disabilities or problems that the child might have as perceived by the parent or guardian. The problem areas covered here are the same as those on the TQP. The physician then proceeds to inquire in detail about the child's medical history. Covering parental and postnatal periods and any history of injury or illness. Detailed information on potential risk factors for disability is recorded. The medical history section is followed by an observation of function (described below) which is the physician's observation of movements made by the child in a structured sequence of activities. Children judged to have problems on the Observation of Function are given a detailed neurological examination. A detailed physical examination (including a full neurological examination if indicated) follows the observation of Function. Anthropometry (i.e. measurements of height, weight, head circumference, and upper mid arm circumferences) was done by a health assistant for the child and the mother if she was available. Vision was tested using the Land hold C chart for those who could follow instructions. For two year olds and mentally handicapped children, the Sty car screening test was used to test vision. Hearing was tested with an audiometer when possible. For younger children and those who did not respond, the Ewing test was used to assess hearing.

Based on the medical assessment, diagnostic ratings of impairment as well as the presence or absence of disability and its severity were made by the physician. As mentioned, the diagnosis of cognitive impairment and disability was made first independently by the physician and psychologists and then jointly by the physician and psychologists. When a diagnosis of disability was made, a Rehabilitation and Referral Form (RRF, Appendix, G) was to be completed to specify the treatment needs and resources of the child.

The observation of function:

In the course of designing the medical assessment for two stage screening for the rapid epidemiological assessment of neurodevelopment disabilities in children, the study team addressed the question not only of standardizing the assessment, but of minimizing the amount of time which physician's would have to spend in making the assessment. A brief instrument, called the Observation of Function was designed to allow the physician to ask the child to perform a few simple tasks and then determine which child needed a more through assessment. The physician scored the child in five domains (motor, hearing, vision, speech and comprehension. A child whose performance failed or was equivocal on any domain would then be assessed with the full examination. This study was carried out to determine whether a completely normal performance on the observation of function could obviate the need for a complete physical and neurological examination in detecting disabilities, in particular motor abnormalities?

The observation of Function was included within the medical assessment form and explained in the procedure manual. When the physician performed the medical assessment he then performed the observation of function which consisted of a brief set of instructions to:

- Greet the child,
- Observe the child response,

Observe the gait of the child,
Request that the child pick up a small object off the floor (shell or coin) with each hand,
Ask the child to name three or four common objects,
Ask the child to point to body parts, and
Ask the child to copy the drawing of a simple geometric form with a pencil.

The shape of the drawing depended on the age of the child, but the rest of the instructions were the same for all children. The instructions on the study form directed the physician in his observations.

The procedure took two to five minutes. The physician then was instructed to report his assessment of the child's performance in each of several domains. The physician could give a score of normal, abnormal, or uncertain. If the child scored abnormal or uncertain on any of the domains it was considered to have failed the observation of function screen. In addition, the physician was asked whether he thought, based on the medical history and the observation of function whether the child had a neuromuscular, vision, hearing or cognitive impairment. The physician was then instructed to go on to perform a routine physical exam. Then the physician recorded his assessment of the presence or absence of disability in the following spheres-motor (gross and fine motor), cognitive, hearing, vision, speech and seizures.

To test the validity of the observation of function, 462 children between 2 to 9 years were referred for medical and psychological assessment of neurodevelopment disability after their mothers had been interviewed. These children became the sample used to test the validity of the observation of function as a way of shortening the time the physician needed in assessing the neurodevelopment status of the child.

The study tested both the scores on the observation of function and the physician impression of impairment in the child against the same physician's final assessment after performing the physical and neurological examination, and audio logical and vision screening, combined with the results from independent psychological assessment. The measures used in testing the validity of the observation of function alone and combined with the physician's global impression are sensitivity and specificity.

Physicians and Psychologists

The two physicians who were performing medical assessments were a neurologist and psychiatrist during their postgraduate training at one of the major postgraduate institutions in the country. They were trained by and reminded under supervision of a senior academic child psychiatrist / neurologist. The senior physician trained the two physicians in the study protocols, procedure manual, diagnostic criteria and standardized medical assessment instrument. He reviewed the diagnosis of every case on a weekly basis and frequently went into the field with the two physicians performing the assessments. The psychologists were masters level psychologists under the supervision of a senior child psychologist specializing in the study and treatment of neurodevelopmentally disabled children.

Diagnosis of Disability:

The diagnosis of disability for the present study was made using criteria agreed upon during the collaborative conferences and described in the procedure manual for the Medical Assessment Form (Appendix F). The International Classification of Impairment

copies of these instruments may be obtained from the first author

Disabilities and Handicaps (WHO 1981) was taken as the basis and modified and simplified for the present study. As mentioned, disability ratings of 1 indicated normal (no disability), 2 indicate mild disability, 3 indicated moderate disability, and 4 indicated severe disability. The code was disabled or the level of severity. For some of the analysis presented in this report, disability into the category 'serious' disability.

To be a case of severe or moderate fine motor disability a child would be unable to use hand for holding implements and for general purpose and needs help in moving about. While a child with mild disability will have a weak grasp, but can use hands, for daily activities and walk without help, may need assistance in climbing steps. Movement disorder was diagnosed after observation of function and neurological examination.

Visual disability is assessed in a 3-9 year old using the Lanthold eye chart. For 2 year old the Stycar screening tests using beads was followed. A child with severe visual disability is one with more than 20/60 vision or which is not correctable.

To access hearing disability in two years old the Ewing screening test was used. For older children audiometric screening was done. A child with serious hearing disability is one with more than 40 Db hearing loss. (20 Db above measured background level). A child with less than 40 Db loss may have difficulty in hearing.

For seizures disability the physician depends on information given by mother or care-giver. The physicians took a very detailed history to arrive at a diagnostic regarding seizure disability. To have serious seizure disability, the child has to have more than one seizures has to be more than two in the past year irrespective of seizure disability, was made in the analysis. In this report, epilepsy is defined as more than one unprovoked seizure in the child's lifetime.

The evaluation of speech disabilities deals with expressive language only. In the present study this was evaluated separately and not as a an aspect of mental retardation, moderate disability of expressive speech is when the child speaks in single words only but can get across basic needs. A child with severe disability has no speech. While mild disability is diagnosed when a child can speak in simple sentences (depending on age) and can get across basic ideas. Disabilities of articulation are also included. In a moderate articulatory disability a child is understood with difficulty by others, while in sever he or she cannot be understood by others.

Mental retardation was assessed both by the physician and the psychologists. The physician's assessment was based on a detailed history the observation of function, and the child's ability to cooperate & follow instruction during the physical examination and neurological assessment. The psychologists carried out a detailed evaluation of cognitive functioning using a battery of tests. The final diagnosis of mental retardation and the degree of deficit was based on consensus between the physician and psychologists. Generally psychologists decision about the level of cognitive functioning were given greater weight. In some cases, when there was lack of information or cooperation of the child, the psychological evaluations had special relevance and final decisions were made accordingly.

Pretesting of Instruments:

Pretesting of the instruments was undertaken and necessary changes were made at collaborative meetings held in New York. The survey forms were translated into Urdu, back translated to check for discrepancies, revised, and trained in the field by the interviewers. Some minor locally relevant changes were made. This task was accomplished by the second week of July 1987.

Pretesting of the MAF was undertaken with the supervision of one of the principle investigators, Dr. Zaki Hasan.

Five subtests of the Stanford-Binet were pretested and problems of administration and discrepancies due to cultural and educational factors were reviewed and discussed with Drs. Lillian Belmont and Elizabeth Hagen. The necessary changes were incorporated in the test procedures. The underlying principle for acceptable changes was they do not affect the original test procedures, for the obvious reasons that in case it did, the results would not be comparable. At the same time efforts were made to provide conditions for the maximum performance of the child being tested.

Adaptive Behavior Scales were developed and tested. Limited item analysis was done and the scale revised accordingly. The items were selected to be developmentally meaningful for children in Karachi. This work was completed in June 1987. The DDST was also tried in the field.

Data Entry and Management:

The data from all the forms were entered into dBase III+ files on a micro-computer (IBM XT with RAM up to 640K with dual drive and 10 MB Bernoulli was available for data entry and analysis). A full-time data entry person for the period of data collection and cleaning was employed. A part-time programmer / statistician was employed a link the data from different files and assist with other management data tasks and various analysis. Each week the completed forms were checked and entered in the computer. Cleaning of the entered data could only be undertaken on completion of the failed work as it required time consuming checking of each form. Data checking was carried out in three stages. First the printouts of all the files were checked against the files for entry errors. Next, logical checks were made through computer programs. Finally, all the files were checked and linked for the final analysis. The data were stored on Bernoulli cartridges and back-up copies were made on floppy disks.

Training:

Since suitably trained psychologists are not available in Karachi, selection and training of psychologists was a major task, and was undertaken as the first preparatory step for the project. Practical training in administration of tests and decision making was provided. Due to the shortage of time each psychologist hired was generally trained to administer only two of the four tests used, the Stanford-Binet, the DDST, the Adaptive Behavior Scale, and the CDQ. The duration of collecting the normative data provided an excellent opportunity for the psychologists to get training and experience.

The interviewers available and selected did not have any previous training or field experience. All were graduates but their fields of education and backgrounds varied. They were given instruction in theoretical and practical aspects of disabilities and associated problems. Techniques of interviewing and developing rapport, and adapting one self to the community being

visited without losing any information being collected were conveyed. The interviewers were particularly trained to administer the survey forms and to elicit accurate information on disabilities. Methods were developed and practiced for collecting accurate information on the age of the mother and particularly the age of the child, as birth certificates were rarely available. The interviewers were given supervised practical experience in the field by the field supervisor, who had extensive pilot study experience.

Two physicians carried out the medical assessments of the children. Both were undertaking postgraduate training at the Jinnah Postgraduate Medical Center. One as psychiatrist and the other a neurologist. The physicians were trained by Dr. Zaki Hasan who is co-investigator of the study and a senior neurologist with a special expertise in neurodevelopment disabilities. The medical procedural manual (Appendix F) was followed and supervised medical evaluations were carried out until the competence required for the work was achieved. The health assistant was trained for the accuracy of anthropometry and hearing and vision tests. This training was supervised by the team physicians. A visit by Dr. Leslie Davidson towards the beginning of the project contributed considerably in clarifying finer aspects of medical evaluation, particularly to the observation of function.

During the normative data collection for the psychological assessment instruments, the entire team gained practical experience and decisions raised by various difficulties encountered were made. Experience in making joint decisions regarding cognitive disability was also gained during this period.

Reliability Checks:

Test-retest and inter-rater reliability data were collected for all of the survey and clinical forms. This involved re administration of the forms and repeat clinical evaluations for a sub-sample of children approximately two weeks after the first interviews and evaluations.

Data Collection:

Field work (the survey and clinical examinations) was carried out five days per week. The sixth work day each week was set aside for discussions, reviews and checking of forms. The psychologists and physicians used this time for discussions for the joint and final decisions on cognitive disabilities.

Problems During the Survey:

Many problems were faced during the project, some expected and some totally unexpected. First, was the unavailability of trained psychologists for the second phase evaluation. As there was none available, psychologists were trained for all the tests used in the survey. It took 3 to 4 months to give the required training to a suitable candidate. Two of the trained psychologists left during the course of the project, and replacements had to be recruited and trained again. The availability of physicians was more consistent.

Second, was the social unrest that prevailed present in Karachi throughout the study period and after. Disturbances and curfews in the city interrupted the fieldwork, and delayed the completion of the project.

A third major problem was cleaning of the data. The volume of data required at least one full-time person responsible for data management. With only one part-time person for this position, cleaning and linkage of the data took much longer than expected.

International Collaboration:

Close collaboration enhanced by meetings and visits by the collaborating experts, has helped considerably towards maintaining the uniformity of the procedures across the sites, creating comparable data and widening the data base for a combined analysis. It also allowed for the genuine differences in the data across the sites to get due emphasis. The New York meeting before the start of the project was most useful, as major decisions and finalization of the evaluative instruments and procedures took place.

The BOSTID meeting in Peru was timely for sorting out issues on sampling, data management and analysis. Consistent support and communication with the collaborative at the Sergievsky Center has been a valuable experience of this project. This intense collaboration in scientific research and unconditional sharing of knowledge and expertise is of great value to the developing countries in conducting meaningful research.

Meetings and Consultative Visits:

The first meeting at the Sergievsky Center in New York was attended by Z. Meher Hasan (Principal Investigator) and Dr. Zaki Hasan (Co-investigator). We discussed in detail all the important aspects of the study.

The second coordination meeting of the REA group in Peru was attended by Z. Meher Hasan. A consultative visit was made by Dr. Maureen Durkin in July of 1987 when the instruments were being protested and useful discussions took place regarding sampling and reliability of instruments as well as field procedures and data entry and analysis. Dr. Leslie Davidson visited in January of 1988 and this proved valuable and inspiring for the physicians. She provided consultations and training in testing hearing and vision in 2 year olds, neurologic evaluation of children with cerebral palsy, and observation of function. Dr. Maureen Black's visit was useful in sorting out many issues raised in the analysis of the psychological tests.

The congress of the International Association for the Scientific study of Mental Deficiency in Dublin in 1988 was attended by Z. Meher Hasan. Although no paper could be presented due to unforeseen delay in departure, valuable exchange with collaborators from the United States, Bangladesh and Jamaica took place. Dr. Zena Stein visited in October 1989. Valuable discussions of issues regarding data analysis took place and plans for papers were outlined.

IV. RESULTS

The Household Survey and Screening

Table 2 gives the number of households surveyed in each of the 12 zones selected along with various household characteristics. It shows that 2760 of the 2807 households selected participated. This represents a participation rate of 98.7%. No household refused to participate, but the interviewers were not able to complete the forms for 47 households because no one, or no one who was competent to answer the questions could be reached after three attempts. Nearly 70 % of the non-participating households were located in zone 10, a rural zone with higher proportion of

agricultural households than any other zone (Table 2). Because of the relatively high non-participation rate in this zone, the values for all variables obtained for this zone are likely to be biased.

The variables 'percent agricultural' in Table 2 is the proportion of households surveyed in which the main occupation of the head of household was agriculture. The overall percent of agricultural households in the sample (8.0%) is not very different from that for greater Karachi as a whole (5, Table 1.). Zones 10, 11 and 12 are the three rural zones selected; as can be seen from Table 2, these three zones have the highest percentage of the population with agricultural occupations. Some of the analysis describes below are done separately for the urban (1-19) and rural (10-12) zones of the 6365 children screened, 621, or 7.2% reside in the three rural zones (Table 4).

Table 2 also gives the percent of households surveyed that are Muslim, the percent that are comprised of nuclear families, the mean number of persons per household, the number of mothers with 2 to 9 year-old children (total and mean per household), and the number of 2 to 9 year-old children (total and mean per household).

Table 3 provides information about the mothers of children in the sample zone, including the total number, the percent who can read newspaper (either easily or with difficulty, the percent who work outside the home, the percent who are married to a blood relative, the percent who have had at least one child die, and the mean number of live births.

Table 4 gives information on the children screened by zone, including the total number, the percent who screened positive, the percent referred to phase II for evaluation, the percent who are boys, and the percent who attend school among children 6 to 8 years of age. The percent screening positive ranges from 13.2 to 20.5 with an average of 14.7%.

Table 5 gives the screening results by age and gender, and Table 6 give the same by urban / rural residence. For all ages combined boys have a higher positive screening rate than girls (16.6 % v. 12.6%, Table 5). Table 6 shows that at each age, and for all ages combined, the percent screening positive is higher in rural areas than in urban (19.3% v. 14.2%).

Table 7, 8, and 9 compare the percent positive on each of the Ten Questions and on the TQ as a whole in various subgroups. The odds ratios and confident intervals indicate whether certain subgroups of the population are significantly more or less likely to have positive responses. Odds ratios significantly different from 1 indicate either that the TQ works differently in the two groups compared (and, therefore, that it might be biased) or that there are true differences in the two groups in the proportion of children that have potential disabilities. The validity and prevalence results presented will help determine whether differences between groups in the proportion with reported problems reflect true differences in disability rates, or reporting error.

In Table 7, which compares boys to girls, the odds ratios for question 9 (unclear speech), question 10 (slow compared to other children) and the overall TQ are significantly greater than 1, indicating that boys are significantly more likely than girls to be positive on these two questions and on the TQ as a whole.

In Table 8, which compares younger to older children, odds ratios for question 3 (hearing) and 10 (slow compared to other children) and for the TQ as a whole are significantly less than 1, indicating that younger children are significantly less likely to be positive on these two questions and the TQ as a whole than older children. The odds ratios for questions 5 (movement disorder) and 6 (seizures),

on the other hand, are significantly greater than 1, indicating that younger children are more likely to be positive on these questions.

In Table 9, which compares urban to rural children, the odds ratios for question 1 (delayed milestone) and 5 (movement disorder) and the TQ as a whole are significantly less than 1, indicating that urban children are less likely than rural children to be positive on these two questions. No other odds ratios are significantly different from 1.

Table 10 summarizes the results of the test-retest reliability study. These results shows fair to high levels of reliability for each of the survey questions analyzed, including the screening result.

B. Phase II: The Clinical Evaluation

Table 11 and 12 give the percentages of children who participated in phase II (the clinical evaluation) among the children referred after phase I (the screen). The results are given for all children and separately for children who were positive and negative on the TQ. Table 11 gives these results by zone and table 12 gives them by age group, gender and urban-rural residence. Overall, 85.8% of those referred for evaluation were evaluated. This percentage was slightly higher for children screened positive than for those who screened negative (87.3 v. 83.6%). The percent evaluated among those referred differs somewhat across the 12 zones (from a low of 72.1 in zone 1, where the study began, to a high of 96.6 in zone 9, Table 11) but is similar across each of the groups compared in Table 12.

Validity of the Observation of Function:

Table 13 summarizes the results of the study to validate the observation of Function. In the sample of 461 children that participated in this validation study, 58.6% screened positive on the Observation of Function. The Observation of Function was designed primarily to screen for moderate and severe motor and cognitive disabilities. For this purpose, the results in table 13 show it has perfect sensitivity (no false negatives) but relatively low specificity (excess false positives). When the criterion is expanded to include mild motor and cognitive disabilities, or to include any type of moderate or severe disability (motor, cognitive, hearing, vision, seizures), the sensitivity drops from 100% to 91-93% and the specificity increases only slightly (from 41-42% to 44-45%). As expected, expanding the criterion further to include any disability (mild, moderate, or severe motor, cognitive, vision, hearing or seizure disability) results in a further reduction of sensitivity (to 81%) and a small increase in specificity (to 50%).

In summary, these results show that the observation of Function is a highly effective screen for serious motor and cognitive disabilities in 2 to 9 year-old children. Because approximately 59% of the children screened positive on the observation of function in this sample, while no cases of serious motor or cognitive disability were missed, we conclude that the screen eliminated the need for a full neurological examination for the remaining 41% of the children evaluated. In the overall two phase study of childhood disability in Karachi, the observation of function was used as a screen, and children who screened negative on it were not given a full neurological examination. The results of this validation study suggest that it substantially increased the efficiency of the physicians responsible for evaluating the children for disability.

Validity of the Ten Questions with Probes for Screening Serious child hood Disability

Table 14-21 present the main findings of the study regarding the validity of the TQP. Table 14 gives estimates of the sensitivity, specificity and positive and negative predictive value of the Ten Questions (without the Probes) for several types and levels of severity of disability. Tables 15-20 give the same estimates in various subgroups of the population. The overall sensitivity (Table 14) indicates that the TQP detects approximately 73% of the seriously disabled children in the population. The sensitivity is highest for serious seizure disability (100%) followed by serious motor (84%) and cognitive (83.5%) disabilities. The sensitivity is modest for hearing disabilities (70%) and lowest for serious vision disabilities (58.5%).

These results suggest that the TQ provides an effective screen for serious seizure, motor and cognitive disabilities for young children in Karachi. However, it does not appear to provide a sensitive screen for hearing and particularly for vision disabilities in this population.

The positive predictive value for any serious disability is 0.229, indicating that 22.9% of those who screened positive were found to have a serious disability. One way of evaluating this level of positive predictive value is to compare it to the prevalence of serious disability in the population. From the data presented in Table 22, discussed below, we see that the prevalence of serious disability in the population is 46.2 per 1000 or 4.6%. The ratio of the positive predictive value to the prevalence in the population is 5 (22.9 / 4.6), indicating that the prevalence of serious disability is five times as great in the children who screen positive as it is in the general population. Furthermore, with only 14.7% of the children screening positive, the TQ effectively reduces the number of children that need to be referred for clinical evaluation. Thus, the TQ is an effective screen for serious disability, particularly for serious seizure, motor, cognitive and hearing disabilities.

Tables 15 and 16 give the validity results for 2 year-olds and for 3-9 year olds, respectively. They show that the overall sensitivity is slightly lower for 2 year-old children than for 3-9 year-olds, but that this difference is not consistent across types of disabilities. For 2 year-olds, the sensitivities are perfect for all types of serious disability except vision, for which the sensitivity is perfect only for serious seizure disability; the sensitivities for the remaining types of disability ranges from 63.5% to 82.1%.

Tables 17 and 18 give the validity results for urban and rural children, respectively. Overall and for each type of serious disability except vision, the sensitivities are higher for rural children than urban. The positive predictive values are also generally higher for rural children.

Table 19 and 20 give the validity results for boys and girls, respectively. For all serious disabilities, the sensitivities are very similar in boys and girls. For each type of serious disability other than seizure (for which sensitivity was perfect for both groups), however, the sensitivities, however, the sensitivities differ between and boys and girls. Among boys the sensitivity is perfect for serious cognitive and motor disabilities but poor for vision and moderate for hearing. For girls the sensitivity is moderate for cognitive and motor and perfect for vision and hearing.

Table 21 shows the effects of using various combination of probe questions on the sensitivity and positive predictive value of the screen for serious disability (i.e, severe and moderate motor, cognitive, hearing, vision and seizure disabilities) and on the percent of the population expected to screen positive. The results in this table indicate that the use of the probes to each question

incrementally improves the positive predictive value and decreases the percent who screen positive and are referred for evaluation. However, these improvements are made only at the expense of sensitivity. In addition to this loss of sensitivity, another unfavorable effect of the probes is the increased complexity they introduce to the screening procedure. The probe questions lengthen the screening questionnaire considerably and make it more difficult for the interviewer to determine whether the child has screened positive or negative. In light of these two unfavorable effects of the probes, neither the small gains in positive predictive value nor the reductions in the number referred for clinical evaluation seem justified.

C. Prevalence Estimates of Childhood Disabilities in Greater Karachi

Table 22 gives the prevalence estimates with 95% confidence intervals obtained from the data for various types and levels of severity of disability. These estimates are given for the total population of 2 to 9 year-old children and separately for boys and girls, younger (2-5) and older (6-9) children, 2 year-old and 3-9 year-old children, and rural and urban children.

For all children, the estimated prevalence of any of the five types of serious disability is 46.2 per 1000. the most frequent types of serious disability in this population are motor (19.5/1000) and cognitive (19.0/1000). The latest common was seizure (5.0/1000) and hearing (5.2/1000). The sum of the estimated prevalence's of individual types is greater than that of "any serious disability" because of the occurrence of multiple disabilities in some children.

There are two sets of significant differences (i.e., with non –overlapping confidence intervals) in estimated prevalence between the vrious sub-populations compared in Table 22:

- (1) Boys have significantly higher prevalence's than girls of serious vision and hearing disabilities and of all disabilities combined ("any serious disability"), but there is no significant difference between boys and girls in the prevalence of cognitive and motor disabilities.
- (2) Children in rural areas have significantly higher prevalences thand those in urban areas of serious motor and cognitive disabilities and of all disabilities combined ("any serious disability") The point estimates of these prevalences are more than twice as high in rural areas than urban. The point estimates of the prevalences of the vision, hearing and seizure disabilities are also higher for rural than urban children, but these differences are not statistically significant.

Table 23 summarizes the validity and prevalence results for any impairment (i.e., any motor, cognitive, hearing, vision, or seizure impairment, regardless of whether the child was disabled). The TQP is not designed to detect impairments that do not result in disability, thus, it is not surprising that the sensitivity of the TQP for detecting all impairments is only 19.1%. The fact that the positive predictive value for any impairment is higher than the prevalence of impairment in the population (77.9% v. 60.0%) suggests that the TQP does help select a sub-population with more impairments than the general population. Further analysis will be done to determine whether the TQP is more sensitive for detecting selected types of impairments than others. If it is effective at detecting impairments that eventually result in disability when no intervention is made, it is possible that the use of the TQP could provide a tool for early detection that could enable primary prevention of disability.

V. Summary and Conclusion

Study Population and Data Collection:

Twelve of the 59 zones that make up Greater Karachi were selected for the survey, with probability of selection proportionate to their size. Nine of the 12 zones were selected from among 43 urban zones and the remaining 3 zones were selected from among 16 rural zones. In the 12 zones, a total of 2760 households with 2 to 9 year old children were selected for the study. Twenty-seven hundred and sixty or 98.7% of these households agreed to participate. All 2 to 9 year-old children residing in the 2760 households were screened with the TQP during phase I of the study. In all, 6365 children were screened. Fifteen hundred and seventy-six of these children were referred to phase II of the study for clinical evaluation. Of these 1576 children, 85.5% actually participated in the phase II evaluation.

Reliability:

A test-retest reliability study of the data collected on the survey, screening and clinical evaluation forms found moderate to high levels of reliability for most variables, and at least fair reliability for variables examined.

Validity of the Ten Questions:

The results indicate that the TQ is a sensitive screen for serious seizure, motor and cognitive disabilities in 2 to 9 year-old children in Karachi. It has modest sensitivity for serious hearing disability and poor sensitivity for serious vision disability. For seizure, motor and cognitive disabilities is an effective screen because it reduces the number of children requiring a clinical evaluation from 100% to only about 15% of the population. The positive predictive value observed in this study is five times greater than the prevalence's of serious disabilities in the general population, which indicates that the screen is effective in selecting a sub-population in which the prevalence of serious disability is very high.

In summary, the validity of the TQ is adequate for serious seizure, motor, and cognitive disabilities in situations when all children who screen positive are referred for a more definitive clinical evaluation. However, with a positive predictive value of 22.9%, the TQ cannot be used alone to determine whether a child is disabled. For serious hearing and especially vision disabilities, the TQ appears to be a less than adequate screen because of its relatively low sensitivity.

Effect of the Probe Question:

The probe questions do improve positive predictive value and reduce the number of children screening positive and requiring a clinical evaluation. However, these improvements are modest and made only at the expense of sensitivity. Because of this loss of sensitivity, as well as the increased complexity to the screening procedure introduced by the probe questions, the use of the probes does not seem justified.

Prevalence:

The overall estimated prevalence of serious disability among 2 to 9 year-old children in Greater Karachi is 46.2 per 1000, or nearly 5%. Motor and cognitive disabilities are the most common (19.5 and 19.0 per 1000 respectively), followed by vision (15.1/1000). Serious hearing and

seizures disabilities are the least common (5.2 and 5.0 per 1000, respectively) . The prevalence estimates for all disabilities combined are higher in boys than in girls, and more than twice as high in rural areas as in urban.

Future Analysis:

Future data analysis will attempt to : (1) examine why certain cases of serious disability were misses the screen; (2) describe the occurrence of multiple disabilities; (3) describe the needs for treatment and rehabilitation in this population; (4) identify major risk factors for each of the five main types of disabilities studied; and (6) describe the prevalence and identify risk factors for specific conditions, such as epilepsy, cerebral palsy and others.

Benefits of the Project:

A major of the project was the development of useful tools for screening and diagnosing childhood disabilities in Pakistan. Another benefit was the expertise and experience gained by all members of the research team. A third benefit is that the data generated from this project provide an in-depth understanding of childhood disability in Karachi and a data base where non existed previously. Future analysis of this data base will attempt to identify the major risk factors childhood disability in Karachi. the results presented here as well as the results of future analysis of the data will have direct relevance to the planning of rehabilitation services for disabled children in Karachi and of programmes for primary prevention .

Table 2**NUMBER OF HOUSEHOLDS IN THE SAMPLE AND SELECTED HOUSEHOLD CHARACTERISTICS BY ZONE**

Zone	No. of Households Selected for Survey	Completed Among Households Selected	Agricultural	Muslim	% Nuclear Family Household	Mean No. of Persons per Households	No. of Mothers* (Mean per House)	No. of 2-9 yrs. Children (Mean per House)
		n %	%	%	%		n n	
1	357	354 (99.2)	1	77	60	8	385 (1.09)	838 (2.3)
2	349	347 (99.4)	6	86	60	8	358 (1.03)	834 (2.4)
3	349	349 (100)	2	98	69	8	359 (1.03)	815 (2.3)
4.	349	345 (98.8)	3	99	74	7	354 (1.03)	834 (2.4)
5	346	345 (99.7)	0	100	62	7	358 (1.03)	738 (2.1)
6	342	341 (99.7)	2	100	65	8	353 (1.04)	778 (2.3)
7	80	80 (100)	3	91	66	7	80 (1.00)	187 (2.3)
8	199	199 (100)	1	100	76	8	203 (1.02)	487 (2.4)
9	100	100 (100)	0	100	68	8	102 (1.02)	233 (2.3)
10	99	74 (74.8)	77	100	71	6	75 (1.01)	161 (2.2)
11	181	181 (100)	47	100	77	7	182 (1.01)	370 (2.0)
12	45	45 (100)	49	100	62	7	50 (1.11)	90 (2.0)
Total	2807	2760 (98.7)	8	95	67	8	2859 (1.03)	6365 (2.3)

Number of Mothers with 2 to 9 Year-old Children living in the Household

Table 3**SELECTED MATERNAL CHARACTERISTICS BY ZONE**

Zone	Numbers of Mothers with 2.9 Year-old	Can Read	Work outside Home %	Married to Blood Relative %	Have Had >= 1 Child Die %	Mean no of Live Birth
1	385	58	11	55	24	4.6
2	358	21	4	76	37	4.9
3	359	40	3	69	32	5.2
4	354	43	3	64	34	4.8
5	358	81	3	40	16	4.1
6	353	63	5	51	28	5.2
7	80	46	3	56	30	5.0
8	203	45	3	39	35	5.5
9	102	61	3	52	34	5.1
10	75	4	4	77	48	4.5
11	182	10	22	92	52	5.3
12	50	6	12	92	32	4.6
Total	2859	46	6	60	31	4.9

Table 4**SELECTED CHARACTERISTICS OF CHILDREN SCREENED BY ZONE**

Zone	No. of 2-9 Year-old Children Screened	% Screened Positive	% Referred for Evaluation	% Boys	% who Attend School Among Child Older than 5 Years
1	837	13.9	24.4	52	86
2	834	13.2	22.9	51	52
3	815	13.7	23.8	52	78
4	833	16.5	26.8	57	76
5	738	13.7	23.8	54	88
6	778	13.5	23.1	54	84
7	187	19.3	28.3	51	74
8	487	13.3	23.4	55	67
9	233	14.6	24.9	53	79
10	161	19.3	29.8	48	28
11	370	20.5	30.5	57	68
12	90	14.4	23.3	58	61
Total	6365	14.7	24.7	54	75

Table 5**NUMBER OF CHILDREN SCREENED AND % POSITIVE BY AGE AND GENDER**

Age	All	% TQ+	Boys	% TQ +	Girls	% TQ+
2	858	9.9	467	10.9	391	8.7
3	862	14.0	481	16.4	381	11.0
4	865	16.5	467	18.6	398	14.1
5	790	14.6	425	17.9	365	10.7
6	841	17.8	453	19.4	388	16.0
7	790	15.4	412	18.0	378	12.7
8	808	14.7	417	16.3	391	13.0
9	551	14.9	301	14.6	250	15.2
Total	6365	14.7	3423	16.6	2942	12.6
%	100%		54%		46%	

Table 6**NUMBER OF CHILDREN SCREENED AND % POSITIVE BY AGE AND URBAN / RURAL RESIDENCE**

Age	All	% TQ+	Rural	% TQ +	Urban	% TQ+
2	858	9.9	98	15.3	790	9.2
3	862	14.0	93	17.2	769	13.7
4	865	16.5	77	27.3	788	15.5
5	790	14.6	78	21.8	712	13.8
6	841	17.8	84	16.7	757	18.0
7	790	15.4	88	18.2	702	15.1
8	808	14.7	64	15.6	744	14.7
9	551	14.9	39	28.2	512	13.9.
Total	6365	14.7	621	19.3	5744	14.2
%	100%		10%		90%	

Tables 7

NUMBER AND PERCENT ON EACH OF THE TEN QUESTIONS BY AGE GROUP ODDS RATIO INDICATING RATIO OF THE ODDS OF SCREENED POSITIVE ON EACH QUESTION IN YOUNGER CHILDREN TO SAME ODDS IN OLDER CHILDREN

Questions	Number (%)	Younger (2-5) (%)	Older (6-9) (%)	Odds Ratio	95% C.I
1. Milestone	284 (4.5)	151 (4.5)	133 (4.4)	1.006	0.793-1.277
2. Vision	82 (1.3)	36 (1.1)	46 (1.5)	0.690	0.455-1.070
3. Hearing	73 (1.1)	25 (0.7)	48 (1.6)	0.457	0.281-0.744
4. comprehension	34 (0.5)	19 (0.6)	15 (0.5)	1.123	0.570-2.214
5. Movements	158 (2.5)	97 (2.9)	61 (2.0)	1.421	1.028-1.965
6. Seizure	177 (2.8)	114 (3.4)	63 (2.1)	1.624	1.189-2.218
7. Learning	58 (0.9)	32 (0.9)	26 (0.9)	1.091	0.649-1.835
8. No speech	57 (0.9)	34 (1.0)	23 (0.8)	1.313	0.772-2.234
9. Unclear speech	347 (5.5)	177 (5.2)	170 (5.7)	1.001	0.809-1.238
10. Slowness	186 (2.9)	63 (1.9)	123 (4.1)	0.443	0.326-0.603
11. Overall TQ+	937 (14.7)	464 (13.7)	473 (15.8)	0.848	0.738-0.974

1. Odds ratio significantly greater than 1 indicate that a greater proportion of younger than older screened positive odds ratios significantly less than 1 indicate the opposite.

Table 8

NUMBER AND PERCENT ON EACH OF THE TEN QUESTIONS BY GENDER ODDS RATIO INDICATING RATIO OF THE ODDS OF SCREENED POSITIVE ON EACH QUESTION IN BOYS TO THE SAME ODDS IN GIRLS

Questions	Number (%)	Boys (%)	Girls (%)	Odds Ratio	95% C.I
1. Milestone	284 (4.5)	167 (4.9)	117 (4.0)	1.238	0.973-1.577
2. Vision	82 (1.3)	48 (1.4)	34 (1.2)	1.216	0.782-1.893
3. Hearing	73 (1.1)	42 (1.2)	31 (1.1)	1.167	0.732-1.860
4. comprehension	34 (0.5)	22 (0.6)	12 (0.4)	1.579	0.780-3.197
5. Movements	158 (2.5)	89 (2.6)	69 (2.3)	1.112	0.809-1.528
6. Seizure	177 (2.8)	106 (3.1)	71 (2.4)	1.292	0.953-1.726
7. Learning	58 (0.9)	36 (1.1)	22 (0.7)	1.411	0.828-2.403
8. No speech	57 (0.9)	35 (1.0)	22 (0.7)	1.371	0.803-2.343
9. Unclear speech	347 (5.5)	222 (6.5)	125 (4.2)	1.593	1.277-1.987
10. Slowness	186 (2.9)	114 (3.3)	72 (2.4)	1.373	1.018-1.852
11. Overall TQ+	937 (14.7)	567 (16.6)	370 (12.6)	1.380	1.198-1.590

1. i.e. positive on any one or more of the ten questions
2. odds ratios significantly greater than 1 indicate that a greater proportion of boys than girls screened positive.

Table 10**TEST-RETEST RELIABILITY COEFFICIENTS**

	N	Reliability Coefficients	Lower 95% C.L
House Hold Form			
Own v. Rent	60	.84	.58
# Possessions	60	.72	.50
# Persons	60	.72	.50
#Rooms	60	.60	.33
Mother's-Child Form			
Mothers Age	57	.56	.28
Mat. Literacy	57	.82	.56
#Live Births	57	.89	.80
Child Died	57	.92	.66
Consanguinity	57	.75	.49
TQP Form			
Child's Age	52	.95	.91
Attends School	52	.92	.65
TQ Results (+/-)	52	.57	.33
Medical Assess. Form			
Consanguinity	73	.69	.46
Hospital Birth	73	.78	.55
Hx. Of Injury	73	.66	.43
Height	73	.99	.99
Weight	73	.99	.99
Cognitive Disability	73	.96	.73
Gr. Motor Disability	73	.78	.55
Fn. Motor Disability	73	.75	.52
Vision Disability	73	.67	.44

Table 11

**NUMBER OF CHILDREN REFERRED FOR EVALUATION AND PERCENT
ACTUALLY EVALUATED AMONG ALL CHILDREN AND BY TQ STATUS, BY
ZONE**

Zone	Total No. Referred	% Evaluated	No. of TQ + Referred	% Evaluated	No. of TQ- Referred	% Evaluated
1	204	72.1	116	69.8	88	76.1
2	191	87.4	110	88.2	81	88.9
3	194	88.1	112	91.1	82	87.8
4	224	91.1	138	91.3	86	91.9
5	176	90.3	101	97.0	75	82.7
6	180	80.6	105	82.9	75	78.7
7	53	90.6	36	91.7	17	94.1
8	114	81.6	65	81.5	49	83.7
9	58	96.6	34	97.1	24	95.8
10	48	85.4	31	83.9	17	88.2
11	113	92.9	76	93.4	37	91.9
12	21	76.2	13	84.6	8	62.5
Total	1576	85.8	937	87.3	639	83.6

Table 12

**NUMBER OF CHILDREN REFERRED FOR EVALUATION AND PERCENT
ACTUALLY EVALUATED BY TQ STATUS AND BY AGE GROUP, GENDER AND
URBAN / RURAL RESIDENCE**

Groups	Total No. Referred	% Evaluated	No. of TQ + Referred	% Evaluated	No. of TQ- Referred	% Evaluated
2-5 Years	807	86.0	464	88.1	343	83.1
6-9 Years	769	85.6	473	86.5	296	84.1
Boys	901	85.6	567	86.4	334	84.1
Girls	675	86.1	370	88.6	305	83.0
Urban	1394	85.4	817	86.9	577	83.2
Rural	182	89.0	120	90.0	62	87.1

Table 13

**THE SENSITIVITY AND SPECIFICITY OF THE OBSERVATION OF FUNCTION IN
KARACHI (N=462)***

Disability	Sensitivity (%)	Specificity (%)
Moderate or Severe Motor Disability	100	42
Motor Disability (mild, moderate or severe)	91	44
Moderate or Severe Cognitive Disability	100	41
Any Moderate or Severe Disability	91	44
Any Disability (mild, moderate or severe)	81	50

The physician's ratings were made before he had performed a physical examination on the child. The physician was instructed not to change his answers after the physical examination was performed.

Table 14

VALIDITY OF THE TQ FOR SERIOUS DISABILITIES

	Any serious disability	Serious cognitive disability	Serious motor disability	Serious vision disability	Serious hearing disability	Serious seizure disability
Sensitivity	.729	.835	.840	.585	.697	1.000
Specificity	.881	.866	.867	.859	.856	.857
Positive predictive value	.229	.108	.111	.060	.024	.034
Negative predictive value	.985	.996	.996	.993	.998	1.000

Table 15**VALIDITY OF THE TQ FOR SERIOUS DISABILITIES IN 2 YEARS OLD CHILDREN**

	Any serious disability	Serious cognitive disability	Serious motor disability	Serious vision disability	Serious hearing disability	Serious seizure disability
Sensitivity	.695	1.000	1.000	.303	1.000	1.000
Specificity	.925	.913	.915	.905	.907	.908
Positive predictive value	.276	.132	.158	.053	.066	.079
Negative predictive value	.987	1.000	1.000	.9987	1.000	1.000

Table 16**VALIDITY OF THE TQ FOR SERIOUS DISABILITIES IN 3-9 YEARS OLD CHILDREN**

	Any serious disability	Any cognitive disability	Serious motor disability	Serious vision disability	Serious hearing disability	Serious seizure disability
Sensitivity	.733	.819	.821	.635	.635	1.000
Specificity	.874	.859	.893	.852	.848	.849
Positive predictive value	.224	.105	.106	.061	.020	.030
Negative predictive value	.985	.996	.996	.994	.998	1.000

Table 17**VALIDITY OF THE TQ FOR SERIOUS DISABILITIES AMONG BOYS, ALL AGES**

	Any serious disability	Serious cognitive disability	Serious motor disability	Serious vision disability	Serious hearing disability	Serious seizure disability
Sensitivity	.730	1.000	1.000	.440	.664	1.000
Specificity	.866	.850	.850	.859	.839	.839
Positive predictive value	.237	.114	.114	.055	.035	.031
Negative predictive value	.983	1.000	1.000	.986	.997	1.000

Table 18**VALIDITY OF THE TQ FOR SERIOUS DISABILITIES AMONG GIRLS, ALL AGES**

	Any serious disability	Serious cognitive disability	Serious motor disability	Serious vision disability	Serious hearing disability	Serious seizure disability
Sensitivity	.728	.644	.644	1.000	1.000	1.000
Specificity	.898	.884	.885	.882	.875	.879
Positive predictive value	.216	.098	.107	.067	.009	.040
Negative predictive value	.988	.992	.992	1.000	1.000	1.000

Table 19**VALIDITY OF THE TQ FOR SERIOUS DISABILITIES IN URBAN AREAS, ALL AGES**

	Any serious disability	Serious cognitive disability	Serious motor disability	Serious vision disability	Serious hearing disability	Serious seizure disability
Sensitivity	.705	.796	.775	.627	.632	1,000
Specificity	.882	.869	.868	.865	.860	.862
Positive predictive value	.206	.096	.085	.062	.021	.031
Negative predictive value	.986	.996	.996	.994	.998	1.000

Table 20**VALIDITY OF THE TQ FOR SERIOUS DISABILITIES IN RURAL AREAS, ALL AGES**

	Any serious disability	Serious cognitive disability	Serious motor disability	Serious vision disability	Serious hearing disability	Serious seizure disability
Sensitivity	.831	1.000	1.000	.375	1.000	1.000
Specificity	.869	.837	.854	.811	.814	.816
Positive predictive value	.380	.185	.287	.046	.046	.056
Negative predictive value	.981	1.000	1.000	.981	1.000	1.000

Table 22**ESTIMATED PREVALENCE AND THE 95% C.I OF SERIOUS DISABILITIES IN CHILDREN IN KARACHI (PER 1000)**

	Any serious disability	Serious cognitive disability	Serious motor disability	Serious vision disability	Serious hearing disability	Serious seizure disability
All Children	46.17 (40.3-52.0)	19.0 (15.3-22.7)	19.5 (15.7-23.3)	15.1 (11.6-18.6)	5.2 (3.1-7.2)	5.0 (3.2-6.9)
3-9 Years	47.2 (40.8-53.6)	19.9 (15.7-24.0)	20.1 (15.9-24.2)	14.8 (11.0-18.5)	4.9 (2.8-7.1)	4.6 (2.7-6.5)
2 Years	39.4 (25.7-53.1)	13.0 (5.1-21.0)	15.6 (6.9-24.4)	17.2 (8.0-26.5)	6.5 (0.8-12.2)	7.8 (1.6-14.0)
All Boys	53.8 (44.9-62.6)	18.9 (14.1-23.8)	18.9 (14.1-23.8)	20.8 (14.7-26.8)	8.7 (4.9-12.4)	5.1 (2.5-7.6)
All Girls	37.4 (29.9-44.9)	19.1 (13.6-24.5)	20.2 (14.6-25.8)	8.4 (4.9-11.9)	1.2 (0.2-2.5)	5.0 (2.3-7.7)
Rural	88.3 (63.0-113.6)	35.8 (20.5-51.1)	55.5 (36.7-74.2)	23.9 (7.7-40.0)	9.0 (1.2-16.7)	10.7 (2.2-19.3)
Urban	41.5 (35.6-47.3)	17.1 (13.4-20.9)	15.5 (11.9-19.1)	14.1 (10.5-17.6)	4.8 (2.7-6.8)	4.4 (2.6-6.2)

TABLE 23**VALIDITY AND PREVALENCE RESULTS FOR ANY IMPAIRMENT * BY AGE GROUP, GENDER, AND URBAN / RURAL RESIDENCE**

Groups	Sensitivity	Specificity	PPV	NPV	Prevalence	95% C.I
All	.191	.919	.779	.431	509.7	584.2-615.1
2-5 Years	.180	.925	.778	.435	594.3	573.8-614.8
6-9 Years	.204	.912	.780	.427	605.8	582.6-629.1
Boys	.205	.900	.771	.408	622.0	599.9-644.1
Girls	.173	.938	.790	.457	573.7	552.6-594.8
Rural	.186	.918	.756	.450	579.3	563.1-595.4
Urban	.230	.936	.926	.259	776.5	729.1-824.0

Any impairment refers to any motor, vision, hearing, cognitive or seizure impairment, regardless of whether the child is disabled. See page 12 of the MAF, Appendix E

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Appendices

- A. Household Form (HF)
- B. Mother-Child Form (MC)
- C. Ten Questions with Problems (TQP)
- D. Child Disability Questionnaire (CDQ) Revised, 22 items
- E. Medical Assessment Form (MAF)
- F. MAF Procedure Manual
- G. Rehabilitation and Referral Form (RRF)

Table 1. Karachi Municipal Area and Population

Total Area	1361.8 Square Miles
Number of Urban zones	43
Number of Rural zones	16
Total Number of zones	59
Total Population	7,642,695
Population in Urban zones	7,204,990 (94.3%of total)
Population in Rural zone	437,705 (5.7%of total)