THE INTERNATIONAL PILOT STUDY OF SEVERE CHILDHOOD DISABILITY.

Final report: Screening for severe mental retardation in developing countries.

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Bishop Bekkers Foundation
for activating the care for the
mentaJly retarded

Bishop Bekkers Institute
for the promotion of research
into mental retardation

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FOREWORD

Dr. Lillian Belmont's Final Report contains the harvest of five years of concerted work on the International Pilot Study of Severe Childhood Disability. The Bishop Bekkers Foundation and the Bishop Bekkers Institute are pleased to present these results to all who are concerned with the well-being of mentally retarded persons living in developing countries.
The main product of the Study is an instrument for the assessment of severe mental retardation in the developing world. It should be useful for planning, prevention and intervention purposes.

Support to endeavours such as the International Pilot Study is very much in keeping with the aims of the Bishop Bekkers Foundation and the Bishop Bekkers Institute.
The Bishop Bekkers Foundation engages in fund-raising and in activating the care for the mentally retarded in the Netherlands and in the international field, by giving organisational, public relations, and financial support to promising new initiatives. It derives its name from the late RomanCatholic Bishop, Mgr. WM. Bekkers, whose person and work has become a symbol for broadminded ecumenical openness and for society's active concern for the underprivileged in general and for the mentally retarded in particular.
Sensing the insufficiency of research efforts at the time, the Bishop Bekkers Foundation was party to the establishment of the Bishop Bekkers Institute in 1972, and remains, next to the Dutch government, its main subsidizing body.
The Bishop Bekkers Institute promotes research on mental retardation and on mental retardation services by stimulating new research projects, co-ordinating them, as well as by publishing a scientific quarterly in Dutch and providing library services. Its acti vi ties do not stop at the Dutch border, but include initiating and taking part in international co-operative research efforts. The choice of the subject resulted from consultations with research workers in the end of the 1970's. There appeared to be a clearly felt need for information on the prevalence of severe mental retardation in developing countries, for purposes of planning, prevention and intervention. This need could only be met by devising new, adequate assessment methods.

Eminently, the International Pilot Study of Severe Childhood Disability has been such an undertaking. Its succes is due to the expertise and sheer hard work put in by a great number of people, as well as to the support received from a variety of organisations. Communication and co-ordination between them have been facilitated by regularly held meetings (Doorn, The Netherlands, 1980; Bangalore, India, 1981; Nairobi, Kenia, 1983).

Now, at the successful completion of the International Pilot Study, we owe a debt of gratitude to all who have been engaged in it.
In the first place, Dr. Lillian Belmont is to be congratulated on her outstanding work in preparing and co-ordinating the fieldwork, as well as for the analysis and the reporting of the data. Her employers should be praised in the person of P~ofessor Zena A. Stein, Director, Epidemiology of Brain Disorders Research Department, New York State Psychiatric Institute, and Professor Mervyn Susser, Director, Gertrude H. Sergievsky Center, Columbia University, New York, for putting in their scientific, financial and logistic resources and international contacts to ensure the success of the Study.

Admiration and thankfulness is due to the project directors: Professor Sultana Zaman (Bangladesh), Professor Benjamin Schmidt (Brasil), Professor H.S. Narayanan (India), Dr. Rebecca George and Dr. Mohammed Sham Kasim (Malaysia), Ms. Heidi Larson (Nepal), Dr. Zainab Meher Hasan and Dr. Khalida Tareen (Pakistan), Professor Charlotte Floro (Philippines), Dr. A.D. Nikapota (Sri Lanka) and Professor Robert Serpell (Zambia) for having borne the brunt of the execution of the project together with their assistants, and for accomplishing the results.

We should like to thank the Scientific Advisory Group of the International Pilot Study in the person of its Chairman, Professor A.D.B. Clarke of the Universi ty of Hull, for expert advice on setting up and monitoring the study; among the members of the Group we are especially indebted to Dr. Ann M. Clarke and Professor Robert Serpell for their help in devising the screening instrument and for their comments on the interim results of the Study.

Acknowledgments for their goodwill and active support are rendered to Dr. Annalise Dupont, President, International Association for the Scientific Study of Mental Deficiency; to tJ'JrS. Susan Hammerman, Secretary General, Rehabilitation International, to Dr. Michael Irwin, formerly Senior Adviser on Childhood Disabilities, UNICEF, and to Dr. Helmut Sell, Regional Director of Mental Health, WHO, New Delhi, India.

It is to be trusted, that the International Pilot Study will be followed by vigorous action to put the results of the research into practice for the benefit of mentally retarded persons and their next of kin.

December, 1984

Bishop Bekkers Foundation

Dr. A.L.M. Knaapen, Chairman,
Mr. E.J.N. Felix, Commissioner

Bishop Bekkers Institute

Dr. C.G.A. de Jong, Chairman
Dr. S.M. Nemeth, Director

INTRODUCTION

The Report outlines the results of a unique collaborative cross-cultural study on the prevalence of severe mental retardation in 10 study sites in 9 developing countries. Childhood disabilities know no national boundaries, and impose both suffering and an eoonomic burden on victims, their families and society. They also reflect wasted human potential, for in theory at least, many handicapping oonditions are preventable, or if not prevented, the functioning levels of the retarded can often be raised by appropriate training or treatment. In those large areas of the world where for many normal persons their very existence is marginal, such notions, arising from researoh and practice in the Western World, seem utopian. However, a start must be made, and the first step is represented by a study, such as this in which three questions are addressed: (1) how do we assess severe mental retardation in the developing world; (2) what is the extent of the problem; (3) and what oan we do about it? This international pilot study provides some preliminary answers, with reference particularly to the first and seoond questions.

The need to establish the prevalenoe of ohildhood disabilities in the Third World had been disoussed by several research workers in the mid-1970s. The first step was to bring together interested soientists to discuss feasibility. The initiative was taken by the Bishop Bekkers Institute in August, 1979, when it hosted a meeting in Jerusalem during the 5th Congress of the International Association for the Scientific Study of Mental Deficienoy. This was rapidly followed by the first of three Workshops supported by the Institute in May 1980, held at Doorn, The Netherlands. Disoussions there, and a year later in Bangalore, led to more precise plans and the development of two instruments of substantially differing length for establishing the presenoe or absence of disability in young children. The comparison of the reliability of these instruments has provided important results which may be utilised in the future.

For comparable data to be available oross-culturally, it was, of course, neoessary to establish culture-free assessment devioes, more easily said than done. The solutions focussed on the universals of human development such as motor abilities, speech and comprehension, vision and hearing, as well as significant medical history.

Among other things, the Report indicates both the usefulness of this approach and the difficulties encountered. Important recommendations are outlined, snd it is clear that, as a pilot study, the program has been highly sucoessful.

The author of this Report and her colleagues have completed a very valuable task. The many persons in developing countires who collaborated with the New York team also deserve congratulation. It is very pleasant to note that the Bishop Bekkers Institute's initiative led to further sponsorship by the New York Psychiatric Institute and Rehabilitation International/UNICEF Technical Support Program. Disoussions in Delhi will help to chart the direction of future work in this important area.

A.D.B. Clarke
Chairman, Advisory Group

International Epidemiological Studies of Childhood Disability

COLLABORA TING BODIES

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Institute

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THE INTERNATIONAL PILOT STUDY

OF

SEVERE CHILDHOOD DISABILITY

FINAL REPORT: Screening for Severe Mental Retardation
Prepared for the
Bishop Bekkers
Foundation-International Workshops

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Final Report: The International Pilot Study of Severe Childhood Disability

SUMMARY

The International Pilot Study of Severe Childhood Disability was completed at 10 sites in nine developing countries: Bangladesh, Brazil, India, Malaysia, Nepal, Pakistan (Karachi and Lahore), the Philippines, Sri Lanka and Zambia. The major focus of the Pilot Study was to determine whether it would be possible, in developing countries, to identify children with severe mental retardation and other disabling conditions, by means of short questionnaires. This was accomplished in a house-to-house survey, which was followed by professional examinations of (a) children who screened positive on the questionnaires, and (b) a small random sample of normals, children who screened negative on the questionnaires. The research included a rehabilitation/intervention component for the children who needed help. We also wished to determine whether a key informant approach to case finding (in contrast to the house-to-house survey) would be useful in bringing to notice children with severe mental retardation and other disabling conditions.

The rationale for studying severe mental retardation in developing countries was expressed at the First Bishop Bekkers Workshop (held in the Netherlands, May, 1980). Participants at the Workshop recognized that there is little information on the extent of severe mental retardation in developing countries, and that these countries would soon need to become aware of this problem in order to plan services and institute preventive programs. It was thought that it might be feasible to study severe mental retardation in developing countries if a suitable screening instrument were devised.

The Pilot Study was a collaborative effort between principal investigators and their teams at study sites and a number of other bodies: the Bishop Bekkers Foundation Workshops, the New York State Psychiatric Institute, Rehabilitation International/UNICEF Technical Support Program, and the Sergievsky Center, Columbia University.

This final report presents an overview which assesses the effectiveness of two.screening questionnaires in bringing to notice children with severe mental retardation, summarizes other components of the Study, and offers recommendations with respect to future studies of severe mental retardation in developing countries.

The Pilot Study represents the first large-scale attempt to begin the collection of systematic information on severe mental retardation and other disabling conditions in developing countries. Common procedures and common instruments were used at all study sites, in order to achieve comparability.

Two screening questionnaires (which had to be translated into local languages) were developed for the Pilot Study and used at all sites: (1) a short questionnaire, in a yes-no format, consisted of Ten Questions (TQ), four

concerning the child's vision, hearing, movement and seizures and six concerning the child's cognitive competence; (2) a somewhat longer questionnaire, the Child Disability Questionnaire (CDQ) which covered the same areas as the TQ, but contained more questions concerning cognitive competence.

A detailed procedure manual served to guide investigators through the various phases of the Study. At each site (except one), during the house-to-house survey approximately 1000 children, in the age range 3-9 years, were screened, using the two questionnaires, the TQ and the CDO. Different interview instructions were provided for younger (3-6 year old) and older (7-9 year old) children. Interviews about younger children used both the TQ and the CDQ; interviews about the older children were mainly done with the TQ. (If an older child had problems on the TO, the CDQ was used; the CDQ was also used for a random selection of older children who had screened negative on the TQ, i.e. had no problems.)

The house-to-house screening survey was followed by a professional assessment (done "blind", i.e. without knowledge of the questionnaire status of the children examined) of children who screened positive on one or both questionnaires. A small proportion of randomly selected presumed normals (screened negative on both questionnaires) was also assessed. It would have been desirable to have all children in the house-to-house survey professionally assessed, but this was not a viable alternative, largely because of scarce resources. The assessment of the random sample of normals would need to stand for the total number of children who had screened negative.

The professional assessment served two objectives: (1) the outcome of the professional assesssment could be used to validate the two questionnaires, the TQ and the CDQ; (2) a rehabilitation plan could be formulated for children who needed help.

For present purposes, the diagnosis of severe mental retardation (SMR), made at the professional assessment, was the criterion against which the questionnaires were validated. The results reported refer to 8 of the study sites from which we have verified diagnoses. (Data regarding other diagnoses were less fully analyzed.)

Major analyses concern the estimate of the sensitivity of the questionnaires, taken separately, (and separately for the two age groups) for the population of children at each of the 8 study sites. Sensitivity may be defined as the percentage of children professionally assessed as severe mental retardation who screened positive on the questionnaire (TO or CDQ). It was found that there was perfect (100%) sensitivity for SMR at the majority of the study sites for the TQ and almost so for the CDQ. Sensitivity at the remaining sites was adequate to poor on one or both questionnaires or for one age group. (The estimates of sensitivity are unstable because it was not possible to examine a larger number of children.) The overall findings on sensitivity led us to conclude that there now exist tested questionnaires for use in future studies.

We hoped it would prove feasible to use only one questionnaire, the shorter TQ, in future studies. We therefore analyzed the data further and showed that the use of the TQ alone would be an effective screening instrument

to bring to notice children with other disabling conditions, in addition to severe mental retardation.

With respect to rehabilitation plans for children who needed help, it was found that various intervention/rehabilitation/referral schemes to serve both individuals and communities were proposed at the various sites. Systematic analyses of these will be detailed in a later report.

With respect to the key informant approach to case finding, we noted that this approach had very limited usefulness in this study. (However, this method did not receive the same care and attention as was given to the house-to-house survey.)

RECOMMENDATIONS:

1. We recommend that in future studies one questionnaire, the TQ, be used as the sole screening instrument. We expect that the TQ would select about 10% to 30% of children for more detailed evaluation. Those selected for evaluation should include virtually all SMR childrn, in most situations. The scre~n will also bring to notice chidren with other problems (i.e. the TQ is not specific for SMR). Among the children who screen positive who do not have SMR, a sizable proportion will have other disabilities. This is probably an added strength of the screen since, in practice, a survey intending to stimulate interventions will not aim to affect only one disability.

2. We recommend that the CDQ be considered for use as part of the professional assessment.

3. We recommend that the professional assessment be more fully developed.

4. We consider it highly desirable that a research program be initiated aimed at the development of uniform standards by which to judge severe mental retardation and perhaps other disabling conditions of childhood •

Since those involved in developing rliagnostic procedures are often the key figures in stimulating rehabilitation, we recommend that the nature of appropriate interventions, and their evaluations, form an integral part of this research program.

5. In future studies, it would be useful to maintain periodic face-to-face contact with study site investigators.

6. It could be important to explore the circumstances, clinical correlates, and history of each SMR child, compared to an age-sex matched unaffected child. Such case-control studies would represent a relatively inexpensive additional activity to the survey and would for the first time give a notion of "cause."

SECTION I

INTRODUCTION

The International Pilot Study of Severe Childhood Disability was completed at 10 study sites in nine Third World countries. The aim of the study was to determine whether it would be possible to identify, by means of short questionnaires, three-to-nine year old children who had a variety of disabling or potentially disabling conditions and particularly severe mental retardation. The pilot study included a rehabilitation/intervention component for children who needed help.

The Pilot Study was a collaborative effort between principal investigators and their teams at study sites and a number of other bodies: the Bishop Bekkers Foundation-Workshops, the New York State Psychiatric Institute, Rehabilitation International/UNICEF Technical Support Program, and the Sergievsky Center, Columbia University.

This final report of the Pilot Study traces the events as they pertain to the Pilot Study from 1980 to the present; describes the study sites; evaluates the effectiveness of two questionnaires, used in a house-to-house survey, validated against professional assessment; discusses the use of a key informant approach; and concludes with a discussion of the usefulness of the undertaking, with suggestions on possible next steps.

A. HIS'I'ORY

The goals of the International Pilot Study were formally expressed at the first Bishop Bekkers Workshop on mental retardation, convened in Doorn, The Netherlands in May 1980. The Workshop brought together a number of experts on mental retardation. The participants recognized that there is little information on the prevalence of severe mental retardation in developing countries and that countries needed to become aware of this problem in order to plan services and institute preventive programs.[1] It was also argued that as countries become more industrialized and populations migrate to urban centers, the care of disabled children becomes excessively burdensome. One feature of the Pilot Study was therefore an emphasis on intervention for children who need help. The experts gathered at the First Bishop Bekkers Workshop thought it might be feasible to study severe mental retardation in developing countries if a suitable screening questionnaire could be devised.

The papers by the members of this workshop were published in the spring 1981 issue of the International Journal of Mental Health.[2]

As a parallel development, very much in line with the recommendations of the group in the Netherlands, Rehabilitation International prepared a report, in May 1980, for the executive board of UNICEF, on the prevention and rehabilitation of childhood disability. The acceptance of that report led to a new series of UNICEF activities in this area. The Rehabilitation International/UNICEF Technical Support Program was formed and this program collaborated with the evolving study.

After the Hay 1980 Workshop, a series of practical activities were undertaken by Workshop members. A screening questionnaire was developed (by Lillian Belmont and Ann Clarke), colleagues were asked to pretest the questionnaire, and contacts were made with other international organizations,

in particular, the World Health Organization.

Two additional workshops were convened by the Bishop Bekkers Foundation Workshops. The Second Workshop was held in Banga10re, India in May, 1981. A report was given on the pretesting of the screening questionnaire; the questionnaire did discriminate between known mentally retarded children and normal children. After deciding to study the prevalence of severe mental retardation in less developed countries by mounting a pilot study, the major focus of the meetings was on the formulation of features of the research design. Important for subsequent events was the decision to widen the focus of the pilot study to investigate a broader range of severe childhood disabilities, including cerebral palsy, epilepsy, severe visual and hearing disability, while still preserving a main emphasis on severe mental retardation.

To assure comparability across study sites a standard research protocol was needed with each country using the same survey instruments and in the same way. Working in conjunction with other members of the workshop and with support from the Bishop Bekkers Foundation, Drs. Belmont and Stein (New York State Psychiatric Institute and Sergievsky Center, Columbia University) were asked to assume the responsibility for working through details of the research, preparing documentation, and coordinating the work of the various countries participating in the pilot studies.

The Third Workshop was held in Nairobi, Kenya in November, 1982. Preliminary findings were presented; discussion by pilot study participants and invited experts centered on diagnostic issues. Prof. Robert Serpell was asked to pursue the issue of ascertaining how severe mental retardation was diagnosed across sites and to determine whether a consensus could be reached on the features necessary for the diagnosis of severe mental retardation.

B. COLLABORATORS AND CONSULTANTS

The prime responsibility for the conduct of the Pilot Study was that of the local study site investigators. In addition to obtaining funds to carry out the Pilot Study, these colleagues translated forms into local languages, trained interviewers, and had responsibility for arranging for the professional assessment. The study site investigators are listed below, by country.

Country	Investigators	
Bangladesh	S. Zaman	Associate Professor of Psychology, Dacca University Dacca, Bangladesh
Brazil	B. Schmidt	Professor of Pediatrics, Head, Puericulture and Social Pediatrics Escola Paulista de Medicina, Sao Paulo, Brazil
India	H.S. Narayanan	Associate Professor of Psychiatry, National Institute of Mental Health and Neuroscience, Bangalore, India
Malaysia	R. George	Pediatric Consultant, General Hospital, Kuala Lumpur, Halaysia
	M.S. Kasim	Assoc. Professor, Deputy Dean, Faculty of Medicine, National University of Malaysia
Nepal	H. Larson	UNICEF Officer
Pakistan (Karachi)	Z.M. Hasan	Clinical Psychologist and Associate Professor, Department of Neuropsychiatry, Jinnah Postgraduate Medical Center, Karachi, Pakistan
Pakistan (Lahore)	K. Tareen	Child and Fammily Psychiatry Unit, Department of Pediatrics K.E. Medical College, Lahore, Pakistan

Philippines	C. Floro	Professor, School of Allied Medical Professions, University of the Philippines Manila, Philippines
Sri Lanka	A.D. Nikapota	Senior Lecturer in Child Psychiatry, University of Sri Lanka, Colombo, Sri Lanka
Zambia	R. Serpell	Professor of Psychology, University of Zambia Lusaka, Zambia

At the Sergievsky Center, a small core of research workers had defined responsibilities for planning, central coordination and central analysis of the results of the Pilot Study. Dr. Patrick Shrout, Associate Professor of Biostatistics, has been responsible for data analytic techniques and for the statistical analyses contained in this report. Dr. Sten Vermund, a pediatrician with experience in international health, evaluated the medical portion of the professional assessments. Dr. Zena Stein serves as our main adviser and maintains liasion with outside groups. The two full-time workers are Lillian Belmont, and up until recently, Ms. Robin Flam (advanced graduate student in epidemiology).

Colleagues from many countries were generous in their advice concerning various features of the research. We had help from the several members of the Bishop Bekkers Workshop (Prof. A.D.B. Clarke, chairman, Dr. J.M. Berg, Dr. Ann M. Clarke, Dr. Annalise Dupont, Dr. Thomas Fryers, Prof. Peter Mittler, Dr. H.S. Narayanan, Prof. Ignacy Hald) and particularly from the Workshop organizer, Dr. Sandor Nemeth and the Bishop Bekkers Foundation. We acknowledge the help and encouragement, too, of Prof. Mervyn Susser, Director, Gertrude H. Sergievsky Center. Among the Columbia faculty, and at the Sergievsky Center, we consulted with Dr. Thomas Fay, Dr. W.A. Hauser, Dr. Richard Masland, Dr. Richard Neugebauer and Dr. Nigel Paneth. Prof. Ira Belmont (Yeshiva University) acted as consultant through most phases of the

undertaking. We also had help from WHO (Dr. Philip Graham. Dr. Norman Sartorius. Dr. Helmut Sell) and various UNICEF officers. Mrs. Susan Hammerman. Secretary General. Rehabilitation International. advised us and helped in various ways to expedite the delivery of material from study sites.

C. RESEARCH DESIGN OF PILOT STUDY

1. Screening Instruments

We wished to determine whether the same questionnaires (translated into local languages) and the same procedures could be used across countries to identify children with disabling conditions. particularly severe mental retardation. Two questionnaires were used in the Pilot Study: (1) a short questionnaire. in a yes-no format. consisting of TEN QUESTIONS (TQ). four concerning the child's vision. hearing. movement and seizures. six concerning the child's cognitive competence; this questionnaire was developed by Drs. A.M. Clarke. L. Belmont. H.S. Narayanan. and H. Sell. at the meeting in Bangalore. India in 1981; (2) a somewhat longer questionnaire covering the same areas but containing more questions concerning features of mental retardation (developmental milestones. toilet and feeding habits. language. a standardized observation of the child's behavior. and the interviewer's observation of the child). We named this longer questionnaire the Child Disability Questionnaire (CDQ); it was developed by L. Belmont and A.M. Clarke. The CDQ focuses heavily on cognitive competence.

We hoped that because of the universal nature of the behaviors asked about on both questionnaires. they would serve as instruments not bound by cultural differences (as are 1.0. tests) and thus as adequate means for the identification of children with severe mental retardation across Third World countries. The rationale for the construction of the CDQ is detailed e1sewhere.[3]

A description of the major method of case finding, the house-to-house survey and the professional assessments, follows. (Another approach to case finding, the key informant method, was also used; it is described separately in Section III.)

2. Research Design

A standard procedure manual was developed as a guide through the various phases of the Pilot Study. (The Appendix contains copies of the questionnaires, other research forms, and the procedure manual used in the Pilot Study.) Briefly, during the house-to-house survey interviews were to be conducted at each site concerning 1000 children in the age range 3-9 years, using the two questionnaires (TQ and CDQ). For all 3-6 year old children both questionnaires were used; for the older children (7-9 year olds) the interview included the CDQ for those who screened positive (had problems) on the TQ. In addition, for a random sample of older children for whom no problems were reported on the TQ, the interview also included the CDQ. Thus, for the largest proportion of 7-9 year olds only TQ information was collected. We hoped to determine whether the TQ alone would be sufficient for the identification of children with disabling conditions. Along with the two questionnaires, a small amount of personal-demographic data was collected.

The field interviews were followed by professional assessment of some of the children, by a physician and also by a psychologist, if one was available. We prepared a standard set of forms for the assessment. Study site investigators reported that the professional assessments were done "blind," i.e. without the examiner knowing the questionnaire status (positive or negative) of the children professionally assessed. (Of course, if the examiners were aware of the research design, they would know that it was more

likely that a given child had screened positive, since only a small proportion of "normals" were to be seen.)

The professional assessment served two objectives: (1) the outcome of the professional assessment could be used to validate the two questionnaires, the TQ and the CDQ; (2) a rehabilitation plan could be formulated for the children who needed help.

All children who had even one problem on the TQ or CDQ, as well as a random sample of presumed normals (no problems reported on TQ/CDQ) were to be scheduled for professional assessment. For the most accurate validation of the questionnaires, it would have been desirable to have all children assessed. However, it was recognized that this was not a viable alternative, largely because of scarce resources. The assessment of the random sample of negatives (normals) would need to stand for the population at large.

We asked that the data collected during the field interviews and the professional assessments from all sites be sent to us at the Sergievsky Center.

* * *

We asked study site investigtors to complete a questionnaire concerning the conduct of the Pilot Study (the house-to-house survey, the professional assessments and the key informant method) at each site. Also investigators had prepared reports of their experiences in conducting the Pilot Study and the results obtained. (These reports were circulated by Dr. Sandor Nemeth in 1983). The information we gleaned from these sources is incorporated in section lIon the house-to-house survey and professional assessments and in section IlIon the key informant study.

SECTION II

mUSE TO HOUSE SURVEY;

PROFESSI<»fAL ASSESSMENTS

The major effort of the Pilot Study was devoted to the house-to-house survey and the professional assessments of the children who screened positive on the questionnaire(s) and of a random sample of presumed normals, who had screened negative on the questionnaires.

A common procedure manual was used across study sites. The procedure manual contained information on administrative and clerical tasks, on recruitment and training of personnel, as well as explicit instructions on how and which children were to be selected for professional assessment. There were also sections devoted to data analysis and report writing. (The procedure manual is in the Appendix).

By and large, study site investigators found most procedures straightforward. The house-to-house survey progressed smoothly, with cooperation from informants and few refusals or adverse comments. Interviewers did call back, when necessary, to interview informants who were not available on first contact. At most sites the house-to-house survey was completed in about 6 weeks (in 1982). Interviewers reported that they were more co~ortable with the TQ than with the CDQ, because with the CDO they had to read out 3 choices of answers to most questions. The time required for the

CDQ was considerably longer than for the TQ.

There were some difficulties and problems reported regarding study procedures.[4] At some sites, staff expressed difficulty in deciding which children screened positive on the CDQ (we provided a "score sheet" for this task), and also in selecting the random sample of normals for professional assessment. In the event, it seemed to us that at most sites approximately the expected proportion (5%) of "normals" appeared for professional assessment, and we assume they were randomly chosen.

Some children who were scheduled for professional assessment did not appear for the examination. Some had left the area, others could not be found at the address recorded. The inability to assess some children who should have been assessed could have affected the analyses/interpretation. This is discussed below.

Finally, from all sites we received reports of natural disasters and political events which delayed the study at one point or another.

Despite these problems and difficulties, however, the study was completed at 10 study sites and the data forwarded to us at the Sergievsky Center, a major accomplishment for all involved.

A.. BACKGROUND INFORMATION

1. Study Sites; Numbers of Children

In Table 1 we list the study sites, numbered from 01 to **10.** These numbers were assigned in the approximate order of the receipt of the data. (In subsequent tables study sites retain these same numbers.) Included in Table 1 are the number of children for whom there are questionnaire data, and the number of children who were professionally assessed. Except for Nepal, there are at each study site well over 900 children about whom there is questionnaire information. Indeed at the India study site information was collected on more than 1400 children.[5] (Actual interviews may have been conducted for more children; the numbers in the table refer to completed/forwarded records).

Table 1 also shows that there is wide site-to-site variation in the number of children seen for professional assessment. The children who were to be seen for professional assessment were those who had one or more problems on either or both questionnaires as well as a small number of presumed "normals." The variation in the number of children seen was due to two factors: (1) differing numbers of children were said to have problems at the various sites; (2) not all children who should have been seen for professional assessment kept their appointment to be seen, for a variety of reasons. In addition, at some sites investigators had to include for professional examination siblings of the children scheduled to be seen. (The protocols of such unscheduled children were removed from data sets.)

2. Area Chosen for Study; Interviewers; Population Characteristics

On Table 2 we list, for each study site, the kind of area (rural vs. urban) chosen as the study site, the kinds of interviewers used, and finally some few characteristics of the children and their families.

Across study sites, about half were rural and half urban.

Different numbers and kinds of interviewers were used at the various sites. At some sites interviewers were college level people, either students (Malaysia) or professionals (nurses, psychologists, social workers, teachers). In many situations, these individuals had previous experience in conducting surveys and were therefore considered to.be good choices as interviewers. Community residents or community workers were used at the Philippines, Bangladesh, Sri Lanka, Karachi and India study sites. The interviewers used in India were child development workers with special qualifications. At some sites (e.g., Bangladesh, Karachi) field supervision was by professionals who worked along with community residents. It is of particular interest to note that 46 mother community workers served as interviewers at the Philippines study site. We think it would be useful for future studies to know more about these women.

With respect to social characterstics of the families studied, there were two questions asked of all informants: (1) Whether the informant could read a newspaper (which we have used as a gross measure of literacy) and (2) whether the child being inquired about was attending school. In addition, the interviewer was to rate the living standard of the household on a scale from 1 (best) to 4 (worst). Again, this is a very crude measure, but we have included

information on this variable nonetheless.

In the last three columns of Table 2 we present the data derived from these questions and ratings. The proportion of informants who said they could read a newspaper (% literate) varied from 29% to 92%. We tabulated the proportion of older children who were attending school; a very small proportion (14%) of rural Zambian children were in school whereas in Bangalore, India 96% of the children were in school. At the other sites school attendance varied within these limits. The proportion of households said to have the worst living standards was particularly high (36%) in the Bangladesh and India villages.

3. Study Coordination

At various phases of the study, we tried to maintain contact with all investigators by means of correspondence. This proved to be, at times, an inadequate method, and may be basis of some of the questions which were left unanswered.

In future studies, one might provide for a "roving coordinator" to maintain face-to-face contact with study sites and their teams.

B. PREPARATION OF THE DATA FOR ANALYSIS

1. Questionnaire Data

The material used in the field interviews was precoded. These data were sent to us on IBM key punch cards or on tape. Checking for coding and punching errors was to be done by the study site investigators. An ongoing task of the coordinating center was the cleaning of the data. To that end, omissions and errors (invalid codes) were ascertained, and investigators contacted about any problem or inconsistency discovered in the data. Where possible, the investigators checked their original records for us. The whole procedure was extremely time-consuming both for the investigators and for us but given the field conditions, was probably unavoidable.

2. Exclusions

We report on eight of the study sites who participated in the pilot study; for these sites we have verified diagnoses. At study site Ola (Nepal) we were unable to secure verified diagnoses because of a series of unforeseen circumstances. A second, rural, sample was later surveyed and we eventually received questionnaire data and professional assessments for this group. The analysis of these data is delayed because many ID numbers on the professional assessment forms do not match the ID numbers on the questionnaire data. Dr. ~1aureen Durkin-Longley is currently pursuing these issues and is in contact with the study site investigator.

At study site 07, (Lahore), the data on the first thousand children surveyed has been analyzed and reported by Dr. Khalida Tareen. We have not included these data in our analyses because a

random sample of presumed normals was not included for professional assessment and we are therefore unable to make estimates of sensitivity and specificity of the instruments for this study site.

3. Professional Assessments

The completed professional assessment forms were sent to us. All forms needed to be coded and ID numbers checked so that a match could be made between the questionnaire data and the professional assessment data for a given child. It was our responsibility to link the questionnaire data with the professional assessment findings.

Certain problems emerged in the process of linking the two data sets. In some cases, the age recorded on the professional assessment form differed from the one which appeared on the questionnaire data. These age differences were not related to the lapse of time between the house-to-house survey and the professional assessment. Then there were children who were part of the professional assessment procedure but did not have CDQ information. These children were usually, but not always, children who had screened negative on the TQ. Rather than discard such records, we chose to include them. So, for example, if a child screened negative on the TQ and was said to have a problem during the professional assessment, we called him a False Negative whereas if he had no problem, we called him a True Negative. A parallel procedure was used for children who screened positive.

Once the clerical problems were sorted out, diagnostic lists were prepared indicating what we took to be the investigator's diagnosis for each child. This procedure was not always straightforward. Frequently symptoms were recorded but no diagnosis. Some study site investigators included milder conditions, others did not. Sometimes

there were differences between what two examiners (physician and psychologist) considered to be mental retardation, or if mental retardation was indicated by both examiners, there was a difference in grade (i.e. severe or mild). A past history of febrile seizures was sometimes a diagnosis, sometimes not. Common symptol~ of mild visual problems were sometimes diagnosed, sometimes not. We tried to make the diagnostic lists comparable across sites by asking the principal investigators to determine whether a diagnosis (even of mild degree) was warranted when certain symptoms appeared on the professional assessment form. All diagnoses used in the lists were verified by study site invesitigators.

In this report we are particularly interested in the diagnosis of moderate-severe mental retardation (S}m). Because this is the condition of primary importance for our analyses, we studied the professional assessment forms to see how this diagnosis was made. Frequently SMR was associated with severe problems (e.g. cerebral palsy, epilepsy). At times, there were inconsistencies in how a physician and a psychologist would evaluate a child and these disagreements had to be sorted out. They were, but what is sometimes missing from the professional assessment forms is an indication of the features which led to a diagnosis. From our inspection of the professional assessment form, we were not always in agreement with the diagnosis (when there was enough information to make such a judgment). We concluded that there were differences among the sites in the criteria, methods and procedures used in judging severe and mild mental retardation.

Nevertheless~ the on-site investigator's (verified) diagnosis of SMR was used as the criterion to validate the questionnaires.

For each of the eight study sites~ all children were cross-classified by their questionnaire status (positive or negative on one or both questionnaires) and their professional assessment status (seen and diagnosed as SMR, seen and not diagnosed as SMR, and not seen for professional assessment). We expected that the bulk of the children would not have been seen for professional assessment because they screened negative (no problems on TQ and on CDQ, if given) and planned to adjust for this when sensitivity was calculated. However, there were substantial numbers of children at each study site who screened positive on one or both questionnaires and who also were <u>not</u> seen for professional assessment. These children also needed to be included in the total and thus the expected number of cases (diagnosed SMR or not) in this group was estimated.

In the next section, Results, we discuss the findings with primary emphasis on severe mental retardation.

C. RESULTS

The findings of the house-to-house survey and the professional assessments are discussed for the eight study sites from which we have verified diagnoses. Three topics are considered: First we show for each of the eight study sites all diagnoses (e.g.~ mental retardation~ seizures~ vision problems~ etc.) made at the professional assessment. Next we report sensitivity (and specificity) across sites for moderate-severe mental retardation (SMR) only. We conclude with a discussion of the value of the questionnaires first for a diagnosis of SMR~ and then for all diagnoses.

1. All Diagnoses at Professional Assessments

The thrust of this report is on the utility of the questionnaires in bringing to notice severely mentally retaded children; however, we present all the diagnoses made at the study sites, both because of the intrinsic interest and because we are concerned with these diagnoses, too, in considering the utility of the questionnaire (in part 3 below). Tables 3-10 contain the actual diagnoses recorded at the 8 study sites.

Information particular to a study site on the number of children examined and their questionnaire status appears at the bottom of the Tables. This information includes; (a) the total number seen for professional assessment, (b) a breakdown for the number of children who screened positive on one or both questionnaires (or on one where the other was not given) according to whether they had any diagnosis (True Positive) or were considered normal (False Positive), and (c) a breakdown of the children who screened negative on both questionnaires (or on one where the other was not given) according to whether they were considered normal (True Negative) or had any diagnosis (False Negative). These, then, are the definitions used for the initial description of the diagnoses.

In each table the first diagnostic group listed is moderate-severe mental retardation. For the purpose of organizing the results in some reasonable way, we use the following order: moderate-severe mental retardation, ~ild mental retardation, learning disability, cerebral palsy, seizures (epilepsy, febrile fits, past history of seizures), ending with the other conditions (vision, hearing and movement problems, emotional problems). (For the Bangladesh study

site, vision problems, because of high frequency, precede seizures.) Frequently, children had multiple problems. We list the associated problems under the major rubrics which we used. For each diagnostic group, and across all diagnoses, the number of false negatives are listed in parentheses.

At six study sites, there were no false negatives (defined as above) for SMR; however, there were 6 children in India and one in Brazil who had a diagnosis of severe mental retardation but who had entered the professional assessment procedure as part of the random sample of presumed normals (screened negative on the questionnaires). Since only a small random sample of presumed normals was assessed by professionals, it is probable that at some study sites, there were cases of SMR that were not seen for professional assessment and consequently not shown in the tables. In other words, the rate of false negatives could be larger than shown.

Across the eight study sites, the number of children diagnosed as severely mentally retarded at the professional assessment ranged from 5 to 15. At the India study site, 49 children were diagnosed as severely mentally retarded (with six False Negatives).6 (This cannot be accounted for by differences in the numbers of children seen for professional diagnosis.) The pattern at the India study site is clearly different from the other seven sites, but we lack information to decide whether this difference reflects a difference in diagnostic style, a true difference or a combination of unknown factors. This is an important issue which will need to be clarified.

Rather consistently, the group of children professionally assessed as mildly mentally retarded contained a large number of false

negatives, children who entered the professional assessment procedure as part of the random sample of presumed normals. We concluded that our screening procedures permitted an underenumeration of mildly retarded children. By contrast, the relatively few false negatives for SMR suggest that, by and large, the procedures were more adequate in screening for severe mental retardation than for mild mental retardation. It is, of course, to be expected well be that the problems of severely mentally retarded children are more apparent to parents.

One major purpose of the pilot study is to estimate how well the questionnaires, taken separately, would have been able to identify as positive those children who were diagnosed as severely mentally retarded if all children had been seen for professional assessment. (that is, the sensitivity of the screen). The relative sensitivity of the TQ and the cnQ for younger (3-6 year olds) and older (7-9 year olds) children is considered in the next section.

2. Sensitivity and Specificity

The sensitivity of the two questionnaires was calculated separately so that they could be compared, and separately for younger and older children because different selection procedures were used for the two age groups. Sensitivity is the proportion of true cases who would be correctly identified by a screen. Since all children were not seen at the professional assessment, the estimation of sensitivlties required adjustments for the sampling design.[7] The estimates of the sensitivlties are shown in Table 11.

In addition to sensitivity, Table 11 also shows the specificity of each instrument by age group. Specificity is the proportion of children who truly are not cases and who are correctly identified as non-cases by the screen. Since the majority of children in each study site were said to be non-cases by both TQ and CDQ, the specificities in Table 11 tend to be high for both TQ and CDQ. These specificities can be used to calculate the number of children who would screen positive, but who would not be diagnosed SMR on actual assessment, i.e. the false positives. Since the focus of this report is the identification of cases, the discussion below will be limited to sensitivity.

Among younger children, three to six year-olds, there is perfect sensitivity for SMR at five sites, meaning that all children who were in due course diagnosed SMR had screened positive on both questionnaires. Thus, for these five sites, a single questionnaire could have been used to identify all cases. At the sixth site, the TQ had perfect sensitivity whereas the CDQ did less well (83%) in screening for SMR.

The results are less clear-cut for older children. Only two sites (Sri Lanka and Brazil) had perfect sensitivity for both questionnaires; an additional two sites (Malaysia, Bangladesh) had perfect sensitivity on TQ; and one additional site (Philippines) had perfect sensitivity on CDQ. Thus, the TQ again was relatively better, achieving 100% sensitivity at four sites, whereas the CDQ has perfect sensitivity at three sites. The values at other sites fluctuate very widely reflecting, in part, the statistical instability of the estimates; as indicated in Note 7, more assumptions were made for

older children (one concerning CDQ status, the other concerning diagnostic status had they been seen). The relatively poor sensitivity for TQ in the Philippines and in Pakistan result from one SMR chjld at each site who did not screen positive on the TQ. The increase in the estimated number of children who would have been diagnosed SMR who screened negative on the TQ accounts for the low sensitivity for TQ at these sites.

Whereas the sensitivity estimates are often based on relatively few children seen for professional assessment, the fact that for SMR perfect sensitivity occurred more often for the TQ than for the CDQ indicates that the TQ is at least as sensitive as the CDQ, and perhaps more so. We wondered, therefore, whether it would be feasible to apply only the TQ in future studies. This has a certain merit since the interview about a child would be shortened considerably. (In the procedure manual, we hypothesized that the TQ alone might serve for older children; as it turned out the TQ was even more effective for younger children.)

3. Feasibility of Screening with a Single Questionnaire

The issue that we explore here concerns procedures for future studies. We advance the agrument that it would be feasible to use just one questionnaire, the TQ, in future work. Our argument is based only on the children actually examined; it concerns what was, not what might have been. It ignores children who were not seen, a proportion of whom might have been SMR. (It will be recalled that in calculating sensitivity, adjustments were made for children not seen, resulting in statistically unstable estimates.)

Table 12 presents across the 8 study sites the number and percentage of three tg nine year--old children who screened positive on the TQ (Part A) and the TQ status of the children who were diagnosed SMR (Part B). Part A shows that the proportion of all children who screened positive on the TQ ranged from 7% to 30%. This suggests that in future prevalence studies of SHRt fewer than 100 or as many as 300 children might need to be professionally assessed from a total of 1tOOO children.

In Part B of Table 12 we summarize the TQ status of the children diagnosed as SMRt across the eight study sites. For each sitet we indicate the total number of children diagnosed SMRt8 followed by the number who screened positive on the TQ (regardless of their CDQ status). The next column includes those few children who screened negative on the TQt but positive on the CDOt and the final column shows the number of SMR children who screened negative on both questionnaires (False Negatives). We use these raw data to speculate what could be expected **if** only the TQ were used in future studies.

If one uses only the TQ to screen in the futuret the data in Table 12 show one child "missed" at each of two study sites (02 and 06)t plus an additional three children "missed" at another study site (08). (All st of courset were identified by the CDQ.) One child at Study Site 09 and six children at Study Site 08 would certainly be missed regardless of the questionnaire used to screen for SMR.

There were four sites (03t 04t 05 and 10) where all SNR children were able to be identified on the basis of the TQ alone. We looked at the range of problems (question number on which child screened positive) on the TQ reported for these children (Table 13). At each

of these four sites with 100% TQ sensitivity, most children screened positive on a number of questions. However, some few children were identified who were positive on only a single item on the TQ, most frequently on the first TQ question, on developmental milestones. This finding underscores the necessity of assessing all children who screen positive on even one of the TQ items.

As shown in Table 12, among all children who screened positive on the TQ, only a small proportion were diagnosed as SMR, which means that many children need to be assessed in order to find the relatively few who are SMR. Is there an additional yield of conditions other than SMR which would make the TQ more useful as a screening instrument?

To get some notion of what might be expected, we looked at the number of children who screened positive on one or both questionnaires and who had received any diagnosis, including SMR; these children were all the True Positives. Across sites, from 81% to 98% of these children tad screened positive" on the TQ (Table 14). An inspection of the True Positives who were missed by the TQ (number of children in last column) showed that, although there are a few severe cases missed, the large majority of such children had milder manifestations (e.g. mild mental retardation, mild visual problems, past history of febrile seizures). Thus, when examining all diagnoses across sites, the TQ was an effective screening instrument.

In summary, the results have been presented in 3 parts. First, we showed all the diagnoses reported for each of 8 study sites. Second, we found that there was variation across sites in the number of children diagnosed SHR. Third, we reported that perfect

sensitivity for SHR was found at the majority of the study sites for the TQ and almost so for the CDQ. Finally, we argued that there was no compelling reason to use both questionnaires and considered what might occur if only the TQ were used in future studies.

TABLE 1

The Number of Children with Questionnaire Data and with Professional Assessments at Each Study Site, Numbered in the Approximate Order of Receipt of Data

Site Buaber	Studl Site	Questionnaires		Professional AsseSSDlents
01a	Nepal - First Shipment	253		39
01b	Nepal - Second Shipment	224		78
02	Philippines	995		147
03	Bangladesh	989		273
04	Sri Lanka	966		122
05	Malaysia	981		144
06	Pakistan (Karachi)	995		138
07	Pakistan (Lahore)	1039		84
08a	India - First Shipment	55~	1432	137
08b	India - Second Shipment	874		
09	Brazil	1050		339
10	Zambia	1126		232
	ALL	10,050		1733

TABLE 3

The Number of Children with Each Diagnosis at the Philippines Study Site

Moderate-Severe Mental Retardation
1 with febrile seizures, malnutrition
1 with cerebral palsy
1 with febrile seizures
1 with speech defect

Mild Mental Retardation
1 with cerebral palsy, febrile seizures

Learning Disability (1 False Negative)

Cerebral Palsy
2 with speech defect
1 with malnutrition

Epilepsy with Speech Defect

Febrile Seizures
1 with movement disorder

Past History of Febrile Seizures (3 False Negatives)
2 with speech defect
1 with cerebral palsy
1 with emotional problem
1 with "other" problem
1 with polio

Past History of Afebrile Seizures

Vision Problems (1 False Negative)
1 with speech defect

Polio

Moderate Hearing Problem

Speech Defect or Problem (2 False Negatives)
1 with hernia
1 with physical malformation

Emotional Problem

Malnutrition
1 with questionable mild mental retardation

TOTAL 38 (7 False Negatives)

		Number examined (n)
Positive on Questionnaire(s)	True Positive (Any Diagnosis)	51
	False Positive (Normal)	62
Negative on Questionnaires:	True Negative (Normal)	
	False Negative (Any Diagnosis)	

TABLE 4

The Number of Children with Each Diagnosis at the Bangladesh Study Site

Moderate-Severe Mental Retardation

1 with spina bifida
1 with mild hearing problem
1 with mild seizures
1 with mild malnturition
1 with severe vision problem
1 with mild epilepsy, moderate malnutrition
1 with mild hearing problem, moderate seizures
1 with hydrocephaly, cerebral palsy
1 with mild malnutrition, moderate epilepsy
1 with moderate hearing problem, mild malnutrition
1 with mild vision problem, mild epilepsy
1 with mild malnutrition, hypothyroidismm
1 with polio, mild seizures
1 with mild vision problem, mild hearing problem

Mild Mental Retardation (18 False Negatives)

13 with moderate vision problem
13 with mild vision problem
14 with mild malnutrition
13 with seizures
6 with mild hearing problem
2 with speech problems
1 with severe epilepsy
1 with moderate malnutrition
11 with hearing problem, vision problem
9 with vision problem, malnutrition
5 with vision problem, seizures
1 with vision problem, movement disorder
3 with seizures, malnutrition
1 with hearing problem, seizures
1 with hearing problem, malnutrition
1 with malnutrition, spinal tuberculosis
1 with vision problem, hypothyroidism

Severe Vision Problem

2 with seizures
1 with malnutrition
2 with hearing problem, malnutrition
1 with hearing problem, seizures

Mild Vision Problem (3 False Negatives)

5 with hearing problem
7 with malnutrition
2 with seizures
1 with seizures, hearing problem
2 with hearing problem, malnutrition
2 with malnutrition, seizures

Seizures

6 with malnutrition
3 with hearing problem
1 with vision problem, malnutrition

Hearing Problem (2 False Negatives)

3 with malnutrition

Malnutrition (5 False Negatives)

TOTAL (28 False Negatives)

Number examined

			n
Positive on Questionnaire(s)	True Positive	(Any Diagnosis)	187
	False Positive	(Normal)	33
Negative on Questionnaires	True Negative	(Normal)	[illegible]
	False Negative	(Any Diagnosis)	[illegible]

TABLE 5

The Number of Children with Each Diagnosis at the Sri Lanka Study Site

Moderate-Severe Mental Retardation
1 with movement disorder
2 with epilepsy
1 with movement disorder and speech problem

Mild Mental Retardation (3 False Negatives)
2 with febrile fits

Developmental Delay with Deprivation (2 False Negatives)

Epilepsy

Febrile Fits

Vision Problems

Hearing Problems

Locomotor Problems

Emotional Disturbance (1 False Negative)

Speech Delay

Cleft Palate

(Hypospadias)

(6 False Negatives)

			n
Positive on Questionnaire(s)	True Positive	(Any Diagnosis)	48
	False Positive	(Normal)	27
Negative on Questionnaires		(Normal)	
		(Any Diagnosis)	

N

TOTAL

TABLE 7

The Number of Children with Each Diagnosis at the Pakistan Study Site

Moderate-Severe Mental Retardation
3 with movement disorder
6 with cerebral palsy, epilepsy
1 with hearing, movement disorder

20 **Mild Mental Retardation** (4 False Negatives)
5 with febrile fits
3 with movement disorders
1 with febrile fits and hearing problems

2 **Epilepsy**
1 with hearing and emotional problems
1 with speech problem

Febrile Fits (6 False Negatives)
1 with vision problems
1 with hearing problem
2 with hearing and emotional problems
1 with speech problem

5 **Vision Problems**

1 **Hearing Problem**

5 **Movement Disorders** (1 False Negative)

2 **Speech Problems** (1 False Negative)

Emotional Problems (1 False Negative)

(11 False Negatives)

Number examined 198

Positive on Questionnaire(s)	True Positive	(Any Diagnosis)	12
	False Positive	(Normal)	98
Negative on Questionnaires:	True Negative	(Normal)	78
	False Negative	(Any Diagnosis)	10

TABLE 8

The Number of Children with Each Diagnosis at the India Study Site

49 Moderate-Severe Mental Retardation (6 False Negatives)
- 6 with physical malformations
- 4 with epilepsy
- 1 with severe vision problem, physical malformation
- 2 with congenital heart defect
- 1 with past history of febrile [illegible]
- 3 with movement disorder
- 1 with malnutrition
- 2 with microcephaly
- 2 with severe vision problem
- 1 with cerebral palsy, epilepsy
- 1 with severe hearing problem

Retardation (16 False [illegible]
- moderate hearing [illegible]

Questionable or Borderline Mental Retardation (2 False Negatives)

8 **Epilepsy**
- 1 with borderline mental retardation

Past Histor of Febrile Seizures (3 False Negatives)

Past Histo of Afebrile Seizures (1 False Negative)

N [illegible]

Severe Hearin Problem with past history of febrile seizures

1 Movement Disorder

1 Emotional Problem (1 [illegible]

Severe Malnutrition

TOTAL [illegible] (29 False Negatives)

Number examined: 137

Positive on Questionnaire(s)	True Positive (Any Diagnosis)	[illegible]
	False Positive (Normal)	8
Negative on Questionnaires	[illegible] (Normal)	[illegible]
	[illegible] (Any Diagnosis)	[illegible]

TABLE 9

The Number of Children with Each Diagnosis at the Brazil Study Site

Moderate-Severe Mental Retardation (1 False Negative)
1 with cerebral palsy, spina bifida
1 with epilepsy, emotional problem
1 with Down's Syndrome, movement disorder
1 with cerebral palsy, epilepsy
1 with clubfoot

Mild Mental Retardation (11 False Negatives)
2 with epilepsy, congenital heart defect
1 with microcephaly, mild hearing problem
2 with epilepsy, speech problem
2 with past history of febrile seizures, mild [illegible]
5 with epilepsy
4 with mild vision problem
5 with mild hearing problem
2 with breathholding attacks or faints
1 with severe emotional problem
1 with past history febrile seizures
1 with past history afebrile seizures
1 with congenital heart defect
1 with cerebral palsy
1 with movement disorder

Epilepsy (2 False Negatives)
2 with severe vision [illegible]
1 with cleft palate
2 with mild hearing problem

Current Febrile Seizures (1 False Negative)

Past History of Febrile Seizures (1 False Negative)
2 with mild vision problem

Past History of Afebrile Seizures
1 with mild vision problem

Breathholding Attacks

Moderate Vision Problem
1 with mild hearing problem

Mild Vision Problems (8 False Negatives)
1 with congenital heart defect
1 with movement disorders
1 with mild hearing problem
1 with speech problem
1 with breath holding attacks

Speech Problems

Mild Hearing Problems

Emotional Problems

Microcephaly, cerebral palsy mild emotional problem

156 (24 False Negatives)

		Number Examined n
Positive on Questionnaire(s)	True Positive (Any Diagnosis)	132
	False Positive (Normal)	123
Negative on Questionnaires	True Negative (Normal)	[illegible]
	False Negative (Any Diagnosis)	

TABLE 10

The Number of Children with Each Diagnosis at the Zambia Study Site

Moderate-Severe Mental Retardation
2 with past history of afebrile seizures
1 with epilepsy, moderate vision problem

[illegible] False Negatives)
[illegible] seizures, mild [illegible]

[illegible] seizures

Epilepsy
1 with hyperactivity
1 with mild trachoma

Current Febrile Seizures
1 with mild trachoma

Past History Febrile Seizures (3 False Negatives)
9 with mild trachoma
1 with mild hearing problem
1 with hyperactivitiy

Mild Hearing Problem [illegible]
1 with Mild trachoma

Moderate Vision Problem (1 [illegible])
1 with movement disorder

Mild Vision Problem
2 with mild trachoma

Mild Trachoma (5 False Negatives)
1 with physical mlaformation

Movement Disorders (1 False Negative)
1 with physical malformation

TOTAL [illegible]

Number examined [illegible]

Positive on Questionnaire(s)	[illegible] (Any Diagnosis)	[illegible]
	[illegible] (Normal)	[illegible]
Negative on Questionnaires	True Negative	[illegible]
	False Negative	[illegible]

Table 11

Estimated Sensitivity and Specificity of the TQ and the CDQ for Severe Mental Retardation for Younger (3-6 Year Olds) and Older (7-9 Year Olds) Children Across 8 Study Sites

		Younger Children		Older Children	
Study Site		**TO**	**CDO**	**TQ**	**CDQ**
02 Philippines	Sensitivity	1.00	1.00	.31	1.00
	Specificity	.88	.82	.90	.86
03 Bangladesh	Sensitivity	1.00	1.00	1.00	.80
	Specificity	.79	.70	.84	.87
04 Sri Lanka	Sensitivity	1.00	1.00	1.00	1.00
	Specificity	.90	.80	.92	.72
05 Malaysia	Sensitivity	1.00	1.00	1.00	.81
	Specificity	.87	.88	.86	.91
06 Pakistan	Sensitivity	1.00	1.00	.40	.90
	Specificity	.90	.89	.89	.92
08 India	Sensitivity	.30	.28	.32	.15
	Specificity	.96	.94	.97	.86
09 Brazil	Sensitivity	.39	.39	1.00	1.00
	Specificity	.72	.84	.66	.74
10 Zambia	Sensitivity	1.00	.83	*	*
	Specificity	.80	.72	*	*

* No SMR children in older age group

Bangladesh

Child Number	Age/Sex	TQ+ Question Number
1	3/F	
2	4/M	
3	4/M	
4	4/F	6
5	5/F	9
6	6/M	4,7,8,9
7	6/M	6,8,9
8	6/M	7,10
9	6/M	9
10	6/M	8
11	7/M	5
12	7/M	6
13	8/M	9
14	8/F	
15	9/M	

Malaysia

Child Number	Age/Sex	TQ+ Question Number
1	4/F	
2	5/M	
3	5/M	
4	7/F	
5	7/M	
6	7/F	
7	8/M	
8	8/M	
9	8/M	
10	8/F	
11	8/F	
12	9/F	
13	9/F	
14	9/F	
15	9/M	

Sri Lanka

Child Number	Age/Sex	TQ+ Question Number
1	3/F	1,5
2	3/F	1,5,7,8,9
3	6/M	1
4	8/M	4,6,7,9
5	8/M	6.7.8.9

Zambia

Child Number	Age/Sex	TQ+ Question Number
1	3/M	8,9,10
2	4/F	4,7,8,9
3	4/F	3,8
4	4/F	1
5	5/F	6,8,9
6	5/M	4,6,7,8,9

Legend -- TQ Question Numbers

1 - Delay sit, stand, walk
2 - Difficulty seeing
3 - Difficulty hearing
4 - Comprehension
5 - Difficulty moving
6
7 - appropriate
8 -
9 -
10 - slow

SECTION III

KEY INFORMANT STUDY

The Pilot Study included a second approach to case finding, the use of key informants. This method was considerably less systematically tested than was case finding by means of the house-to-house survey. At the planning session in Bangalore, in 1981, some thought that it might be possible to circumvent the labors of an elaborate survey by asking key people about disabled children. Of course, if resources are scarce, and treatment is likely to be available to a limited few then there is something to be said in favor of a less comprehensive approach. From an epidemiologic perspective, however, one would first want to establish that identifying disabled children by the key informant method has some relation to information obtained from a more systematic study.

The purpose, then, of the key informant study was to determine whether the use of key informants alone was sufficient to identify disabled children, by contrasting these findings with the results of the more detailed house-to-house survey. Investigators were provided with a series of Seven Questions, (a copy of which is in the Appendix) to use in interviewing the key informants they had selected.

A key informant is generally assumed to be more knowledgeable about the community than are other members, to have an extended social network, perhaps because of social or professional role, and to be a person who is made aware of happenings/problems in the community. It is not known whether the individuals chosen at the various study sites possessed the qualities ordinarily associated with key informants. Their roles most often do suggest that they were appropriate choices.

We asked study site investigators to send us their key informant findings. We wished to know

(a) whether the same children were identified by the key informants as appeared as "cases" in the house-to-house survey and the professional assessment;

(b) whether there was concordance in the children named by different key informants; and

(c) whether all the children identified in the house-to-house survey were also identified by key informants. (ObviouslYt if this occurred there would be no need to conduct more elaborate surveys.)

The information we received about the key informant study is quite variable and therefore does not readily allow for tabular presentation. We prepared a Chart which shows the kinds of indivirnlals used as key informants and outcomes at and comments from the various study sites.

Individuals with different roles were enlisted to participate in the key informant study across the study sites. In one or two places only one kind of key informant was used: school personnel, principals or teachers. Such individuals tended to know only the children with whom they had contact at the school. As Prof. Schmidt wrote, severely disabled children are unlikely to be found in regular school.

Of course, in settings with universal compulsory education, the number of children of school entry age can be counted and a list kept of those who require special services or who are excluded. Under such conditions, probably atypical in most developing countries, school personnel might know about severely disabled children.

Relatively few children were named by key informants. Among those who were named, some or many of them did not live in the study site area. Frequently children older than 9 years were named. Prof. Z.M. Hasan's comment that older children with visible handicap tended to be named may have relevance to most sites.

Another feature which emerged is that in slum conditions, whether urban or rural, the key informants used in these studies tended to know relatively few people, frequently only those living in the same lane. At a city study site (Bangalore, India) Dr. Narayanan wrote that key informants did not know about disabled children and, in fact, a person might not even know about his next-door neighbor. (Bangalore residents contain many government employees who are frequently reassigned to other locales.)

A novel approach was used at the Malaysia study site. There, individuals who were active in the community, particularly as volunteers at the nutrition house (where professional assessments were done) served as escorts to bring children in for their scheduled examinations. (These children were identified during the house-to-house survey.) Among the children they accompanied, the escorts were asked to name those they considered to be "cases. It was not stated whether these escorts interviewed the child or parent or whether they merely observed the child. In the results, it was clear that there was differential perceptiveness among the escorts. The total number of children named (there could be no concordance between informants in this procedure) did

not equal the total number diagnosed as cases.

Consider, however, the Sri Lanka experience. The Sri Lanka study site, located in a rural area, has a health center. Its health officer and nurse were used as two of the key informants. These two individuals knew some (3) of the same children: two severely mentally retarded children, (one with cleft palate, one with epilepsy) and a boy with hypospadias. It is perhaps possible that the physician knew of children for whom some treatment was in progFess (e.g. cleft palate, seizures). The nurse named four additional children, two severely mentally retarded children and two blind children.

Interestingly the third key informant, a school teacher, named different children from those named by the doctor and nurse. The 3 children she named who were part of the house-to-house survey were all mildly mentally retarded suggesting again that severely disabled children will not be found in regular school settings.

Dr. Nikapota wrote that the key informants' "perception of disability differed" from her diagnosis (a point also made by others). Such differences are not in themselves necessarily a problem if such named children are then assessed by a professional. What is compelling, however, is that only 11 children of the 54 (or 40 if one excludes the 14 children with febrile fits; see Table 5) who were called "cases" by the professional assessment procedure, had been named. We can conclude from this result that if the object of the pilot study is to identify <u>all</u> children who need a professional assessment, then the key informant study had about a 30% success rate in the best case.

By and large, most investigators did not consider the key informant procedure particularly useful. Dr. Zaman considered it "of no help," especially since the key informants she used asked each other for the names of disabled children. Others remarked that the results were disappointing. Some

of the inferences individual investigators drew are pertinent: older children with visible handicap tend to be identified, school personnel tend to know only children in their school, and children named did not necessarily live in the study area. Moreover, what emerges strongly is that the use of key informants in crowded areas is not useful because even community workers are not likely to know a large spectrum of the child population. The key informant approach did not appear to work effectively in large or overcrowded locales - and as migration to large urban centers accelerates in developing countries undoubtedly an even greater degree of anonymity will evolve.

* * *

It is likely that the key informant approach to case finding was not adequately tested. A more adequate test of the key informant approach will be forthcoming from the National Campaign to Reach Disabled Children in Zambia (Prof. R. Serpell, director). Serpell used the house-to-house survey as a validation of this large-scale key informant study. The results are not yet available; from the validation study it does seem that not all children were identified by the key informant approach. Whether the key informant method identified additional or different children from those identified in the house-to-house survey is not yet known.

Key Informant Chart

	Key Informants	Outcome and Comment
[illegible]	2 [illegible] principals	Reported learning problems among pupils in school. None of the children part of house-to house survey. School covers wider area than study site.
[illegible]	No [illegible]	
[illegible]	No [illegible] specified	"Key informants unable to identify most of the disabled children." It was noted that results might have been different if mother health workers had been used as key informants; they were excluded because they served as interviewers in the house-to-house survey.
[illegible]	Chairman, [illegible] region of [illegible]	1. Named [illegible] remainder either older [illegible]
	2 Family welfare visitor	2. Did not know area only knew people who sought her out.
	3. Physician, medical officer at health center Additional: 2 school teachers	3. Did not name any children. [illegible] teachers named 6 children; only two were part [illegible] survey, others from adjacent village.
[illegible]	1. Teacher	1. Named 6 children; 3 in survey and diagnosed as cases
	2 Nurse	2. Named 10 children; 7 in survey and diagnosed as cases
	Doctor	3. Named 4 children; all 4 in survey and diagnosed as cases. 3 children were identified by both nurse and doctor. (4 of 5 children with severe mental retardation and two blind children were named.)
[illegible]	8 volunteer health workers who served as escorts for children seen for professional assessment	Information on 15 children (an additional 4 named not seen for professional assessment). Additional key informants did not provide information. (Key informants) "were able to pick out cases of severe disability quite easily from amongst the children who were recalled for review."

[illegible]

	Key Informants	Outcome and Comment
	1. Housewife involved in community welfare work	1. Named 7 children--2 in survey only one disabled. Other children older.
	2 Voluntary social worker	2. Named 6 children--3 in survey, 2 disabled (severely retarded, deaf). One considered normal. Remainder older.
	Mason, active in community organization	3. Named 5 children, all older.
	4. House site--shopkeeper	4. Named 4 children, none in survey.
	Chairman of Committee	5. None named.
10	Teachers and leading shopkeepers	All (number not stated) children identified were part of house-to-house survey; key informants did not name same children. The children named were "cases" at professional assessment "The community workers (i.e., interviewers) were able to find more disabilities owing to their meticulous work."
30 Urban area	Teachers	Named children above 10 years of age. "Pupils [illegible] to be from area in which school is located."
Rural area 1	Village headman School teacher Anganawadi workers (before survey began)	"Anganawadi (child development) workers knew more disabled children."
60	School teachers	Each teacher gave information about his/her pupils. 26 children were named; 11 were 10 years old or older. (It is not clear whether the remaining children were, or should have been, part of the house-to-house survey.) none of the problems noted by the teachers suggested serious problems. "They mostly noted the children with attention problems."
01	No key informant study as such conducted; the Pilot Study at this site is to serve the purpose of validating the Zambia National Campaign to Reach Disabled Children, which was a modified key informant study.	

SECTION IV

DISmSSION OF FINDINGS AND ISSUES; RECOMMENDATIONS

The International Pilot Study of Severe Childhood Disability was the first large-scale attempt to begin the collection of systematic information on severe mental retardation and other disabling conditions, in developing countries. Comparability across sites was sought by the use of common screening instruments and common procedures. All features of the study were carried out by local personnel and directed by professionally trained study site investigators. All study site investigators were dedicated to the goals of advancing knowledge about and improving care for severely mentally retarded children in their countries.

The Pilot Study was completed at 10 study sites in 9 developing countries. Although there were difficulties and methodological problems (which we will discuss below), the fact that data were collected on a large number of children, that children were professionally assessed, that all the data were forwarded to us -- all these represent major accomplishments!

The function of this pilot study was to try out methods and procedures, with the ultimate aim of setting the groundwork for future studies. We present an overview which assesses the successes and the difficulties of this venture. We summarize findings, raise issues and conclude with a series of

recommendations.

A. MAJOR ISSUES

1. Screening Instruments

How well did the questionnaires fulfill their stated purpose of bringing to notice severely mentally retarded children? What difficulties were associated with this result?

At the majority of the study sites the screening instruments were highly successful in bringing to notice children who were severely mentally retarded. The result was more straightforward for younger children. The TQ did a little better than the CDQ. We conclude that there now exist tested screening instruments for use in future studies.

However, there were a few instances in which the questionnaires were not effective (see B.3.c. below).

2. Prevalence

What is the prevalence of SMR in developing countries?

Prevalence estimates from this study yield a minimum rate. Thus the numbers missed by the screen can only be estimated on the basis of children who were screened negative but were professionally examined. The numbers of such children were small at each site, leaving much room for error. Nevertheless, for all sites save one (India) a prevalence of 5 to 15 per 1000 was obtained and may be considered a first approximation.

Note also that the study was designed as a pilot and therefore the samples were not drawn to be representative of the country.

3. Other Disabilities

Did the screening instruments bring in for professional assessment children with disabilities other than SMR?

We paid attention to all the diagnoses reported from the study sites, and listed the kinds of conditions which were diagnosed at the sites. All lists contain both severe and milder conditions. We ourselves are not certain about all of the diagnoses, and have used this information mainly to argue that if another study is undertaken to screen for severe mental retardation, other potentially disabling conditions will also be diagnosed during the professional assessment. This additional yield from the screening procedure increases the utility of the screening instrument.

4. Rehabilitation

Were the children who were identified as severely mentally retarded helped? Were children with other conditions helped?

The last page of the professional assessment forms was devoted to rehabilitation/intervention. At all sites, some comments were included for children who needed help. and these are being analyzed in a separate report. From the community perspective, various intervention/rehabilitation/referral schemes were proposed. For example:

At one study site special classes were established.

At another site, stimulation programs were mentioned as a means to help slow children.

At another site material from the WHO rehabilitation manual, Training the Disabled in the Community, was provided.

Subsequent work will attempt to determine how systematically and persistently such schemes were implemented.

5. Key Informant Approach to Case Finding

Were knowledgeable community people able to name disabled children?

We detailed the experiences investigators reported when they asked presumably knowledgeable people in the community about the disabled children they knew. By and large, the exercise was deemed to be unsuccessful. There was little correspondence between the very small number of children named by key people and the larger number who were professionally assessed as disabled. Some key informants knew of no disabled children, or knew about older children only or only about those with visible handicaps. Although the key informant method of case finding in the Pilot Study did not receive the systematic care and attention given to the house-to-house survey, it would appear that the key informant method of case finding has limited usefulness for case identification.

B. NEXT STEPS; RECOMMENDATIOBS

What recommendations emerge from the Pilot Study?

1. Use of One Questionnaire

We recommend that in future studies one questionnaire, the TQ, be used as the sole screening instrument. In all sites, save one, the questionnaire was sensitive, bringing to notice most SMR children. In surveys conducted in a similar way to the pilot, we expect the TQ would select between 10 to 30 percent of children for more detailed evaluation. Those selected for evaluation (who screen positive on the TQ) should include virtually all SMR children, in most situations. The screen will also bring to notice children with other problems (i.e. the TQ is not specific for SMR). Among the children who screen positive and who do not have SMR, a sizable proportion, will have other disabilities. This is probably an added strength of the screen since,

in practice, a survey intending to stimulate interventions, will not aim to affect only one disability.

The TQ has other important advantages: it is simple to translate, it requires only about 10 minutes to administer, it is relatively straightforward, and it appears to be acceptable to interviewers and families.

2. Other Instruments of the Pilot Study

a. The Child Disability Questionnaire (CDQ) adds little to the sensitivity or the specificity of the screen for SMR, takes longer to administer, and was less readily accepted by interviewers. It does, nevertheless, provide more detailed information of clinical and public health significance. We recommend that the CDQ be considered for use as part of the professional assessment.

b. The professional assessment (medical and psychological) although conceived to some extent as a standardized procedure, could not be fully developed in the context of the pilot study. We recommend its fuller development as a necessary next step, in order to confirm prevalence, investigate cause and initiate rehabilitation.

3. Cogparability across sites

There are three issues to address here.

(a) We were not certain that the diagnosis of SMR was comparable across sites. Frequently the basis for a given diagnosis was not specified. We proposed in our Interim Report that "it would be useful to convene study site investigators to discuss making standards more uniform in judging mental retardation and other conditions ..... Prof. Robert Serpell has begun, via correspondence, to tackle this issue as it relates to severe mental

retardation. The consensus needed could be accelerated if a workshop, perhaps sponsored by WHO, were to be organized (and to assure continuity, chaired by Prof. Serpell).

(b) Are we justified in making comparisons about prevalence of St1R across sites and what might the purposes of such comparisons be? First, studies must be replicated across sites and problems of measurement overcome. After this, international comparisons should be feasible, permitting enquiries about local or regional differences, and their causes.

(c) With respect to comparability, we pointed out that the India study site is different from the others, in regard to the number of SMR children and the percent who screened positive on the TQ. These findings require further investigation. However, the experience of India alerts us to the possibility of deviant findings, and pre-pilot/pilot studies should probably precede every major survey in a new area.

4. Rehabilitation

It is recommended that an emphasis on community-based rehabilitation, using the \VHO rehabilitation manual, Training the Disabled in the Community. and including an evaluation component, be part of rehabilitation efforts. One objective of the survey approach is to discover and investigate affected children; an equally important objective is to stimulate and supervise appropriate interventions. Although local circumstances will probably dictate the form of intervention, still it may be useful to meld discussion of interventions with the workshop recommended for standardizing diagnosis.

5. Study Coordination

The problems encountered by the coordinators were considerable, perhaps the most burdensome being the voluminous correspondence generated by the task. This was a burden to the study site investigators as well. (Busy as they were with their other reponsibilities and concerns, investigators were not always able to reply to our queries). In future studies, it would be useful to designate someone knowledgeable in research and disability who could pay periodic visits to study sites. This would improve feedback on questions that arise and on decisions that must he made.

6. Search for Cause

If further studies are implemented, it could be important to explore the circumstances, clinical correlates, and history of each SMR child, compared to an age-sex matched unaffected child. Such case-control studies represent a relatively inexpensive additional activity to the survey and would for the first time give a notion of "cause."

* * * *

On the basis of these experiences in 9 countries, screening for SMR and other disabilities could now proceed on a wide scale. The TQ could serve as the screening instrument. On its own, the TQ should yield a measure of disability. Combined with professional evaluation and community-based rehabilitation, it could form part of a national plan to serve the disabled. If professional evaluation is developed into a more standardized procedure. prevalence estimates of reasonable validity could emerge. providing intra-country rates and inter-country comparisons.

IIOTES

1. Stein Z. Why is it useful to measure incidence and prevalence? International Journal of Mental Health, 10:1, 14-22, 1981.

2. Severe Mental Retardation Across the World: Epidemiological Studies. International Journal of Mental Health, 10, whole #1, 1981.

3. Belmont L. The development of a questionnaire to screen for severe mental retardation in developing countries. International Journal of Mental Health, 10:1, 85-99, 1981.

4. At a number of sites, the child's date of birth was not known. Frequently guesses had to be made about the child's age. We had anticipated that this might be a problem and allowed for this by asking about the child's age in three different ways.

S. We think that the questionnaire data of the first shipment refers to Banga10re and the second shipment to the rural area, but have not received confirmation on this point.

6. As we did with other sites, we wrote Dr. Narayanan about false negatives, inquiring whether the child's protocol included some uncoded information which might explain why the child screened negative. Dr. Narayanan thought that many of these children had screened positive on the CDQ. Of the 6 false negatives for SMR, 1 child was TQ-, CDQ not given; the 5 remaining children were TQ- with some information on CDQ, but insufficient to be considered as screening positive on the CDQ.

7. The research design was required all the younger children received both the TQ and CDQ but among the older children only a portion of those who were negative on the TQ (TQ-) received the CDQ. It was necessary to estimate the number of older children who screened negative on the TQ who would have screened positive on the CDQ, had they had the CDQ. (The proportion of the older children with TQ-, who were CDQ+ was applied to the TQ-, no CDQ children to obtain the additional number of estimated CDQ+ children.)

Not all children were seen for professional assessment. lve made the assumption that within questionnaire status (i.e., positive on one, both or neither questionnaire) the case status (i.e., case of SMR or not) of children not seen for professional assessment would be like the case status of children seen. While it is possible that these children were different from those who were seen for professional assessment, we have no good reason to believe this is so. The assumption that those not seen by professionals were like those seen is the most parsimonious assumption, and the only one that allows for estimation of instrument sensitivities and specificities. Estimates were obtained of the numbers of cases of SIIR that would have resulted from a professional assessment of all children. From these estimated numbers of cases and non-cases in the whole sample, the estimates of sensitivities and specificities shown in Table 11 were calculated. Note that these estimates are highly influenced by the outcomes of relatively few professional assessments. Thus, the estimates are considerably less stable than estimates obtained from a design in which the whole population is assessed.

The table below shows how we organized the data from each site; data from older and younger children were analysed separately.

TEN QUESTIONS	CDQ	PROFESSIONAL ASSESSMENT RESULTS Positive	Negative	Not seen	Total in Row
Positive	Positive	a	b	c	w++
	Negative	d	e	f	w+_
	Not given	g	h	i	w+o
Negative	Positive	j	k	l	w-+
	Negative	m	n	o	w__
	Not given	p	q	r	w_o

According to the research design, cells c, f, g, h, i and I should be empty for both older and younger children, and cells p, q and r should be empty for younger children. In several sites, however, these cells had small numbers. The research design further specified that among older children only a subsample of those negative on the Ten Questions be given the CDQ; among these children the cell r is expected to contain a fairly large number.

In order to construct estimates of sensitivity and specificity, we first had to estimate the proportion of children who would have been positive on the CDQ, had they been given that second screening measure. We did this by assuming that given the Ten Questions results, those administered the CDQ were similar to those not administered the CDQ, and we applied the proportions of persons positive on the CDQ to those not given that screen~ We next had to estimate the proportion of children who would have been positive on the professional assessment, had the assessment taken place for all children. To do this we assumed that among children who were positive on the TQ and also positive on the CDQ, the proportion positive on the professional review would be the same in the group evaluated and the group not evaluated by professionals. We repeated this inference for each of the TQ/CDQ result combinations represented in the rows of the above table. The estimated counts are shown in the next table; the notation w+. and w_. represent respectively the total number of children who were positive and negative on the Ten Questions.

Constructed Estimates of Results~
Had All Children Been Assessed by All Measures

		PROFESSIONAL ASSESSMENT	
TEN QUESTIONS	CDQ	Positive	Negative
Positive	Positive	$a^* = a \frac{(w++)}{(a+b)} \frac{(w+.)}{(w+++\ w+\_)}$	$b^* = b \frac{(w++)}{(a+b)} \frac{(w+.)}{(w+++\ w+\_)}$
	Negative	$d^* = d \frac{(w+\_)}{(d+e)} \frac{(w+.)}{(w+++\ w+\_)}$	$e^* = e \frac{(w+\_)}{(d+e)} \frac{(w+.)}{(w+++\ w+\_)}$
Negative	Positive	$j^* = j \frac{(w)}{(j+k)} \frac{(w\_)}{(w-++\cdot w\_J}$	$k^* = k \frac{(w-+)}{(j+k)} \frac{(w\_)}{(w-++\ w\_J}$
	Negative	$m^* = m \frac{(w)}{(m+n)} \frac{(w)}{(w-++\ ;\ \_\_)}$	$n^* = n \frac{(w\_\_)}{(m+n)} \frac{(w\_)}{(w-++\ w\_\_)}$

These constructed numbers are used to estimate the sensitivities and specificities. The sensitivity of the Ten Questions is $(a^*+d^*)/(a^*+d^*+j^*+m^*)$ and the sensitivity of the CDQ is $(a^*+j^*)/(a^*+d^*+j^*+m^*)$. The specificity of the Ten Quest~ons is obta~ned by calculating $(k^*+n^*)/(b^*+e^*+k^*+n^*)$, and the specifity of the CDQ is $(e^*+n^*)/(b^*+e^*+k^*+n^*)$.

(Prepared by Patrick E. Shrout, Ph.D.)

8. The number of SMR children (15) at the Malaysia (05) study site reflects the information we were sent. We understand that it is now thought that only 8 children are SMR, the rest being mild or borderline. Because we do not have particulars about which of the SMR children are now considered mild or borderline, we have used the figure of 15 for Malaysia. For the purposes of the present analyses, the import of the reported results for Malaysia in Table 12 would not be altered if there were 8, not 15, SMR children, since allIS (SMR) children screened positive on the TQ. In Table 11, sensitivities would not be altered for younger children (all SMR children screened positive on both questionnaires); for older children, sensitivity for CDQ would remain the same or improve. Tables 6 and 13 obviously contain 7 children who do not belong there.

APPENDIX 1: TEN QUESTIONS SCREEN

APPENDIX II: CHILD DISABILITY QUESTIONNAIRE **(C.D.Q.)**

TEN QUESTIONS SCREEN

Fill in this information before asking the TEN QUESTIONS.

Interviewer number 32 33

Child's name:

Household number 34 35 36

Child number 37 38

Child's SEX: boy(1); girl(2) 39

AGE:

Birthdate (if known) --nay Month Year - (40-45) OR

Age in years as given by mother: "46 OR

Age as estimated by mother: 47

How old was the mother at the birth of this child?
(Enter age in years, estimate if not sure): 4B"119

Does the child attend school now? no(1); yes(2) 50

Number of live births to mother: 51 52

Birth order of this child (e.g., 1=firstborn~ 2=secondborn) 53

Who will ans.rer questions about this child? mother(1); 'father(2); other(3) .54'

Is informant one who mainly takes care of this child? no(l); yes (2); 55

Can informant read a newspaper? no(1); yes(2) 56

Does informant work outside the home? no(1); yes(2) 57

Are the parents of this child related to each other?
(blood relatives before they married)
no(1); yes(2); don't know(9)

Go to next page and ask TEN QUES'l'IOHSexactly as written. Circle the an Siler given.

TEN QUESTIONS SCRF£N

lMRK:

1. Compared with other children, did the child have any serious delay in sitting, standing, or walking?	1 YES	2 NO	(66)
2. Does the child have difficulty seeing?	1 YES	2 ~10	(67)
3. Does the child appear to have difficulty hearing?	1 YES	2 NO	(68)
4, When you tell the child to do something, does he seem to understand what you are saying?	1 YES	2 NO	
5. Does the child have weakness and/or stiffness in the limbs and/or difficulty in walking or moving his arms?	1 YES	2 NO	(70)
6. Does the child sometimes have fits, become rigia, or lose consciousness?	1 YES	2 NO	
7. Does the child learn to do things like other children his age?	1 YES	2 NO	
8. Does the child speak at all (can he make himself understood in words; can he say any recognizable words)?	1 YES	2 NO	
9. Is the child's speech in any way different from normal (clear enough to be understood by people other than his immediate family)?	1 YES	2 NO	
10. Compared WQth other children his age, does the child appear in any way backward, dull or slow?	1 YES	2 NO	

on to-Zi·,. CDQ: to all 3-6 year olds
to all 7-9 year olds .-rith problems
to other 7-9 ye::.tf._C?].. gh~of is 2....J!larkml_!.hi.!~ap;e

Card number 2
1

Name of Child:

Interviewer number -2--3-

Household number 4 5 6

Child number -7- -8-

Sa

I

HE

CHILD DISABILITY QUESTIONNAIRE (CDQ)*

This questionnaire is in 3 sections:

Section 1: Interview with the mother

Section 2: Interview with the child

Section 3: Questions for the interviewer

Please introduce the questionnaire by saying:

"Nm~ I HOULD LIKE TO ASK YOU SOME HORE QUESTIONS ABOUT HOW YOUR CHILD IS GETTING ALONG. ALTHOUGH THESE QUESTIONS SOUND LIKE THOSE HE HAVE JUST DISCUSSED, I HANT TO HAKE SURE WE HAVE ALL THE INFORMATION."

Interviewer:
The questions and choices to be read aloud are in capital letters.
For each question, circle the answer that is chosen. Now go on to page 2.

QUESTIONS FOR FIELD SUPERVISOR

1. Did this child have problems on the TEN QUESTIONS or the cnQ?

1 No

2 Yes

*This (l11C'stionnaire'las prepared by Lillian Belmont) Ph.D.) and Ann H. Clarke) Ph.D_,

LEAVE BLANK

Section 1 (11-33)Blank

Say to the mother:

I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT (name of child)) ABOUT Hm-1 HE HAS BEEN GROHING AND ABOUT HIS HEALTH.

(1) HOH IS THE CHILD GROHING UP? COMPARED TO OTHER CHILDREN HIS AGE IS HE

1 JUST LIKE OTHER CHILDREN HIS AGE (or advanced) -OR-

2 A LITTLE SLOH -OR-

3 VERY SLOW: ACTS LIKE A MUCH YOUNGER CHILD? (34)

(2) LET HE ASK ABOUT SITTING ALONE. COHPARED TO OTHER CHILDREN DID THE CHILD 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? (35)

9 Don't know. (Specify reason):

(3) NOH) WALKING) COMPARED TO OTHER CHILDREN DID (name) WALK WITHOUT BEING HELPED (that is) when no one had to hold his hand or he didn't have to hold on to things)

1 WHEN CHILDREN USUALLY WALK (or earlier) -OR-

2 SOHEWHAT LATER THAN OTHER CHILDREN -OR-

3 VERY MUCH LATER THAN OTHER CHILDREN? (36)

9 Don't know. (Specify reason):

(L.) DOES HE STILL NEED HELP IN WALKING?

1 NO

2 YES (If yes) ask mother why he needs help in walking): (37)

(5) If you have not observed the child talking, say, CAN HE TALK NOW?

1 YES

2 NO (if No, skip question 6) (38)

(6) COHPARED TO OTHER CHILDREN, WOULD YOU SAY THAT 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? (39)

~ Does not apply; child cannot talk

9 Don't know. (Specify reason):

(7) DOES SEE PROPERLY? WOULD YOU SAY,

1 YES -OR-

2, NOT WELL: HE HAS SOME DIFFICULTY IN SEEING -OR-

3 NO: HE SEES VERY LITTLE OR NOTHING? (40)

(8) DOES HEAR PROPERLY? WOULD YOU SAY,

1 YES -OR-

2 NOT WELL: HE HAS SOME DIFFICULTY IN HEARING -OR-

3 NO: HE HEARS VERY LITTLE OR NOTHING? (41)

(9) DOES HAVE FITS, CONVULSIONS, FALLING ATTACKS, FAINTS, OR SEIZURES? (Translator: use tactful language but offer several different words for the condition.) WOULD YOU SAY,

1 YES -oR-

2 NOT NOH': BUT HE HAD THEM BEFORE -OR-

3 NO (42)

9 Don't know. (Specify reason):

LEAVE BLANK

(10) HAS HAD ANY SERIOUS ILLNESSES OR ACCIDENTS? (For example, measles with a high fever, or a bad fall with unconsciousness.)

_1_ NO (If no, circle "7" for second half of question.)

_2_ YES (If yes, ask the mother to describe):

(English Translation) (43)

9 Don't know. (Specify reason):

If YES, ask: DID THE CHILD SEE A DOCTOR OR GO TO THE HOSPITAL AT THAT TIME?

1 YES

2 NO

7 -- Does not apply. (Child did not have serious illness or accident.) (44)

_9_ Don't know. (Specify reason):

(11) DID YOUR CHILD SEEM TO BE DEVELOPING HELL IN THE FIRST FEW YEARS OF LIFE (IN LEARNING AND TAKING CARE OF HIMSELF) AND IS NOW DIFFERENT?

!. NO, SANE DEVELOPMENT NOH AS BEFORE

_2_ YES (ask mother for details and when she noticed a change): (45)

(English Translation)

9 Don't know. (Specify reason):

LEAVE BLANK

(12) DOES HE HAVE ANY (other) HEALTH PROBLEMS?

1 NO

2 YES (If" yes, write them down):

(46)

(English Translation)

BLANK

---LLLL
(47-51)

(13) CAN HE DO THINGS FOR HIMSELF? LIKE EATING, FOR EXAHPLE: CAN HE EAT BY HIMSELF? WOULD YOU SAY,

1 YES, HE FEEDS HIMSELF -OR-

~ YES, BUT VERY UNTIDY AND NEEDS HELP -OR-

2 NO, HE HAS TO BE FED?

(52.)

(14) DOES HE KEEP HlliSELF CLEAN? (Translate: meaning not soil self wi th feces.)

1 YES, AS WELL AS OTHERS HIS AGE -*DR*-

2 SOMETIMES, BUT NOT AUIAYS -OR-

2 NO, HE DOESN'T KEEP HIMSELF CLEAN

(53)

(15) DOES HE BEHAVE LIKE OTHER CHILDREN HIS AGE? WOULD YOU SAY,

1 YES -OR- WOULD YOU SAY,

~ NO, HE ACTS STRANGE?

(If no, in what way is his behavior strange?)

(54)

(English Translation)

NOW I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT HOW WELL HE UNDERSTANDS AND HOH HE LETS YOU KNOH HE NEEDS SOMETHING. (If child cannot speak, circle 7 for question 16 and skip questions 18 and 19.).

(16) DOES HE SPEAK CLEARLY? IS IT EASY TO UNDERSTAND HIM WHEN HE SPEAKS? COMPARED TO OTHER CHILDREN HIS AGE, WOULD YOU SAY

1 HE SPEAKS CLEARLY ENOUGH TO BE UNDERSTOOD BY ANYONE -OR-

2 NOT TOO CLEARLY: HE IS EASILY UNDERSTOOD BY PEOPLE WHO KNOW HIM BUT NOT BY OTHERS -OR- (55)

3 IT IS VERY DIFFICULT TO UNDERSTAND WHAT HE .SAYS?

~ Does not apply: child cannot speak.

(17) HHEN YOU SAY TO HIM "DO THIS OR THAT" CAN HE UNDERSTAND? WOULD YOU SAY,

1 - YES, HE UNDERSTANDS HHAT I ASK HIM TO DO AS WELL AS OTHER CHILDREN HIS AGE -OR-

2 YES, HE UNDERSTANDS HHAT I ASK HIM TO DO BUT I HAVE TO POINT OR REPEAT THE INSTRUCTION -OR- (56)

3 - NO, HE IS NOT ABLE TO UNDERSTAIID EVEN THE SIMPLEST INSTRUCTION?

(18) CAN HE ANSWER YOUR QUESTIONS PROPERLY? WOULD YOU SAY,

1 YES, HE CAN ANSWER AS WELL AS OTHER CHILDREN" HIS AGE -OR-

2 -- YES, BUT IT IS DIFFICULT FOR HIM TO AU<lAYS ANSHER PROPERLY: I HAVE TO REPEAT 1'1Y QUESTIONS OR ASl< THEM IN A DIFFERENT WAY -OR- (57)

3 NO, HE CANNOT ANSI-IER QUESTIONS?

(19) CAN HE TELL YOU IN HIS OHN WORDS HHAT HAS HAPPENED? WOULD YOU SAY,

_1_ YE S, HE TELLS ME ABOUT THINGS JUS I' AS OTHER CHILDREN HIS AGE WOULD -OR-

___2_. YES, BUT HE FREQUENTLY POINTS AND GESTURES BUT SAYS VERY LITTLE -OR- (58)

3 NO, HE CANNOT LET ME KNOW HHAT HAS HAPPENED?

(20) DOES HE GO TO SCHOOL?

~ YES (If yes, ask question 21.)

2 NO (If no, ask question 22.) (59)

(21) **If** yes, ask IS HE DOING WELL IN SCHOOL? WOULD YOU SAY,

! YES, HE IS DOING WELL IN SCHOOL

~ NO, HE IS HAVING DIFFICULTY WITH SCHOOL.

~ Does not apply; child does not go to school. (60)

9 Don't know. (Specify reason):

(22) **If** no, ask WHY DOES HE NOT GO TO SCHOOL, IS IT BECAUSE

1 HE IS TOO YOUNG -OR-

2 THERE IS NO SCHOOL NEARBY -OR-

3 THE SCHOOL IS TOO EXPENSIVE -OR-

4 THEY WOULDN"T TAKE HIM IN. HE IS TOO SLOW -OR- (61)

5 SOME OTHER REASON? (specify) :

(English Translation)

~... Does not apply; child goes to school

9 Don't know. (Specify reason):

LEAVE BLANK

Only ask questions 23 and 24 for children with serious problems.

(23) ARE THERE ANY PARTICULAR DIFFICULTIES YOU OR YOUR FAMILY HAVE IN MANAGING WITH YOUR CHILD?

1 NO

2 YES (If yes, what are the difficulties?) (62)

------------(English Translation)------------

WHAT DO YOU DO? ______________________

(English Translation)

(24) CAN YOU OR SOME OTHER FAMILY MEMBER SPEND EXTRA TIME PLAYING WITH AND/OR TALKING TO THE CHILD?

~ YES (Who, Specify): ______

(English Translation)

2 NO (Why not?) (63)

(English Translation)

This ends interview with mother. Go to Section 2, interview with child.

BLANK (64-80)

LEAVE BLANK.

FOR OFFICE USE ONLY

Card Number 3 (1)

Interviewer number ~ (2,3)

Household number ~ (4-6)

Child number ~ (7,8)

Section 2 (9-15)Blank

To the interviewer:

Questions 25-29 are tasks you ask the child to do. You should observe the child carefully. First try and put him at ease.

(25) Say, CLAP HANDS (Nark "yes" if he follows your instruction; "incorrect" if he does something else; "no" if he does not respond even after encouragement.)

1 Yes (Nark question 26 "7" and go to question 27)

2 Incoaect (what did he do?) (16)

(English Translation)

3 No

(26) If "incorrect" or "no" to question 25 above, show child, saying LOOK WHAT I'H DOING (clap hands), NOW YOU DO IT.

1 Yes

2 Incorrect (What did he do?) (17)

(English Translation)

3 No

7 Does not apply; child clapped hands

(27) Ask the child to do the following:

(a) SHo\~ME YOUR MOUTH

1 Correct

2 Incorrect (points to) (18)

(English Translation)

~ No response

(b) SHOW ME YOUR NOSE

1 Correct

2 Incorrect (points to) (19)

(English Translation)

~ No response

(c) SHOW ME YOUR EAR

1 Correct

2 Incorrect (points to) . (20)

(English Translation)

~ No response

(d) SHOW HE YOUR KNEE

1 Correct

2 Incorrect (points to) (21)

(English Translation)

~ No response

(e) SHOW ME YOUR EYE

1 Correct

2 Incorrect (points to) (22)

(English Translation)

~ No response

(28) Hold up three fingers and say, HOW MANY FINGERS ARE UP?

1 Correct

2 Incorrect (says _____) (23)

(English Translation)

~. No response

(29) Hold up 7 fingers (4 on one hand, 3 on the other) and say, HOW ~~ FINGERS ARE UP?

1 Correct

2 Incorrect (says) (24)

(English Translation)

~ No response

This is the end of the observation of the child. Thank the mother and the child.

To the interviewer:

We are interested in why a child might not have responded to your requests during the interview. In the list of statements below, circle "2" for those statements which describe this child during the interview and "1" for those statements which do I\otapply.

Applies? No	Yes		
1	2	**Uncooperative**	(25)
1	2	**Didn't understand**	(26)
1	2	**Couldn't see**	(27)
1	2	**Couldn't hear**	(28)
1	2	Did not pay **attention**	(29)
1	2	Shy with strangers; mother had to ask questions	(30)

LEAVE BLANK

Section 3

Now that you have interviewed the child's mother and observed the child, would you please answer the following questions. Please answer these questions after the interview when you are alone.

I. Below is a list of terms about physical appearance and behavior. Please circle "2" for any of them which apply and "1" for those which do not apply to this child when you compare.him with children of his age:

Applies? No	Yes	
1	2	Very small head
1	2	Very large head
1	2	Very short
1	2	Does not look like a normal child
1	2	Paralyzed (weak or absent movement in the limbs)
1	2	Makes strange movements
1	2	Can't sit still
1	2	Very aggressive
1	2	Difficult to manage
1	2	Other (Please list): _____

(English Translation)

II. How does this child compare with other children his age?

1 Much like other children or advanced

2 Seems much behind other children

(41)

LEAVE BLANK

III. Is this child so handicapped that he probably will never be able to live without a great deal of supervision?

1 No

2 Yes (42)

If yes, what kind of handicap or handicaps does he have? Please explain:

(English Translation)

If this child is disabled and would benefit from rehabilitation/intervention. write down the advice you would offer. (You will be discussing this with others when the child is examined by your professional team.)

BLANK
(43-80)

THANK YOU FOR YOUR ASSISTANCE.

Household number _____

Child number __

S.2
7/13/81
cmg