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Summary of Conclusions

The primary purpose of data collection is to enable evidence-based decision making to be undertaken and to be able to direct resources efficiently and effectively. However the validation of the data collected is essential to achieve these positive outcomes for the target populations. Cognitive testing of the proposed tools for data collection is the first step in this process.

A set of questions, in this case a module on child functioning and disability, is only as good as the responses that they elicit. In order to determine whether the questions do in fact ‘work’, that is, elicit responses that are within the scope of intention, they must be cognitively tested. For this project, cognitive testing was successfully undertaken to determine whether the proposed set of questions designed to screen children for disability performed as intended. The testing revealed that the questions performed well, with possibly a tendency for over-identification in the behavioural domains.

Cognitive testing also revealed that the wording of the questions must be adapted to particular languages and cultural environments. It is not adequate to simply translate questions into other languages. They must then be cognitively tested in each language before being rolled out. Cognitive testing is a relatively inexpensive but crucial process for validating the data collection.

Also since the proposed procedure is a first stage to screen for children who are at high risk of having a disability, followed by a second stage to more accurately assess their functioning and link them to services, a tendency towards false positives in the first stage screening instrument is much better than a tendency to false negatives. False positives can be weeded out in the second stage.

However, two key issues remain regarding the proposed two-stage procedure for identifying out of school children with disabilities, namely:

- How extensive will the false positives be? Although theoretically they pose no problem, logistically the procedure will be more efficient and economical if they can be minimized.
- What prevalence will these questions uncover? This is important information for designing the logistics dealing with the second stage as the procedure is rolled out across the population.

These issues can only be addressed with a field test.

Besides the target population of children with disabilities, the process has the wider impact of identifying all children who are excluded from the school system (OOSC – out of school children), whether on grounds of disabilities, social prejudice or economic weakness.
Preface

This report on the results of the cognitive testing of a survey module on child functioning and disability was undertaken as part of a larger survey protocol with a specific purpose. The focus of the proposed survey is children not attending school in India and it is those children who would comprise the main target population. Children may not attend school for a number of reasons; among them, the gender of the child, the financial resources of the family and the disability or functional status of the child.

Means to capture the functional status of children have been under almost constant development over the past decades. The Ten Question module was used often in the past as a ‘screener’ for disability; however, this module was not without its drawbacks: using language that was ‘out-dated’ in terms of child functioning and development, and operationalizing an approach that was more in line with a medical model of disability than a social model - as proposed by the International Classification of Functioning Disability and Health (ICF). The model also had a tendency to over identify children with disabilities, which made the recommended procedure, which includes a second stage assessment, inefficient. At the same time, in some countries the number of disabled children missed by the ten questions was also higher than expected. This generated a demand in the disability research community for an improved set of screening questions.

Coincidental with the current Indian project on school non-attenders, the UN Statistical Commission’s Group on Disability Statistics (in association with UNICEF) was developing a module on child functioning and disability for use in survey and censuses and as part of the UNICEF’s Multiple Indicator Cluster Surveys. The questions the UN Statistical Commission’s Group on Disability Statistics and UNICEF were developing were thought to be appropriate for the purposes of this Indian project.

Survey data are only as good as the responses that are derived; and in order for survey responses to be understood, we must have a good understanding of the cognitive processes that respondents go through in determining their response to different questions. These processes are best elucidated through question evaluation and cognitive interviewing procedures. The UN Statistical Commission’s Group on Disability Statistics, with a long history of question design and development experience, has established methodological procedures for question evaluation. This methodology was shared during the week long training workshop held in Mumbai in the fall of 2012.

We believe that the analyses of the cognitive interview results that are the outcome of the question evaluation process will give a better understand of the questions – and the responses that they elicit. We will know if the questions produce responses that are deemed within the scope of intended responses – or if they are being misunderstood or misinterpreted. Only through this process can questions be reliably modified to capture what they are intended to capture and avoid the possibility of excessive false positive or false negative results.

Our colleagues at ADAPT were able to learn the question evaluation techniques we offered and produce results – and a report – that we think is supportive of the module as it has been adapted to the Indian context. It is worthy of further field testing. By field testing on a random sample of the population, we will be able to determine if the patterns of response observed in the cognitive testing
process are born out in a larger population sample — and in this way the survey module will be fully validated.

We believe that the Indian application of the UN Statistical Commission’s Group on Disability Statistics / UNICEF module on child disability and functioning will add substantively to the evidence moving forward with the further testing of the module on an international basis.

Mitchell Loeb
UN Statistical Commission’s Group on Disability Statistics — representing the Secretariat on the Child Disability Workgroup
December 11, 2012
New York
Introduction

The world’s efforts to improve disability measurement and statistics build on a clear mandate to facilitate evidence-based policy formulation by improving the availability, quality and comparability of disability prevalence rates. When disability policy is mandated by law and entitlements are established for the disabled persons, it becomes very important that such measurement is based on sound principles. In 2001, all WHO members adopted the International Classification of Functioning, Disability and Health (aka ICF) as a unified and standard language and framework for the description of disability and health status. It incorporates the standard rules on the equalisation of opportunities for persons with difficulties.

These efforts have led to the development of internationally comparable statistics – a process facilitated by the UN Statistics Commission’s Group on Disability Statistics (UN SC – GDS aka Washington Group on Disability Statistics or WG). The GDS comprises representative from over 100 National Statistical Offices around the world as well as disability research experts. A smaller workgroup constituted to look into the development of a set of questions specifically designed for the child/youth population and attended by representative from about 10 countries, and UNICEF, has developed a 12 domain question set for this sub-population based on ICF.

However there has been a wide discrepancy in the reporting of disability prevalence amongst and within countries. This is principally owing to the lack of a cohesive basis for identifying disability.

This concern was recently highlighted at a high-level intergovernmental ministerial meeting held at Incheon, South Korea on November 23, 2012. The Governments at this High-level Intergovernmental Meeting adopted the Ministerial Declaration on the Asian and Pacific Decade of Persons with Disabilities, 2013–2022, and the Incheon Strategy³ to “Make the Right Real” for Persons with Disabilities in Asia and the Pacific. The Incheon Strategy provides the Asian and Pacific region, and the world, with the first set of regionally agreed disability-inclusive development goals. Developed over more than two years of consultations with governments and civil society stakeholders, the Incheon Strategy comprises 10 goals, 27 targets and 62 indicators. The Incheon Strategy builds on the Convention on the Rights of Persons with Disabilities and the Biwako Millennium Framework for Action and Biwako Plus Five towards an Inclusive, Barrier-free and Rights-based Society for Persons with Disabilities in Asia and the Pacific.

The Incheon Strategy will enable the Asian and Pacific region to track progress towards improving the quality of life, and the fulfilment of the rights, of the region’s 650 million persons with disabilities, most of whom live in poverty. The ESCAP secretariat is mandated to report every three years until the end of the Decade in 2022, on progress in the implementation of the Ministerial Declaration and the Incheon Strategy.

The lack of adequate, reliable and comparable data on disability was a key issue and is highlighted as Goal 8 of the Incheon strategy:

Goal 8: Improve the reliability and comparability of disability data:

Persons with disabilities tend to be unseen, unheard and uncounted. Increasingly in recent years, when they have been counted, definitions of “disability” and “persons with disabilities” that are used for collecting disability data have varied widely in the Asia-Pacific region. Taken together, data

comparisons across countries are frequently unreliable. The Asia-Pacific region needs more accurate statistics on the population of persons with diverse disabilities and on their socioeconomic status. The adequacy of disability statistics would enable policymaking to be evidence-based and support the realization of the rights of persons with disabilities. The Decade is an opportunity to enhance data collection aimed at generating comparable disability statistics over time and across borders. It is crucial that baseline data for the Incheon Strategy indicators are made available to enable effective progress tracking towards the achievement of goals and targets.

The targets in the Incheon strategy which relate to data and statistics are:

**Target 8.A: Produce and disseminate reliable and internationally comparable disability statistics in formats that are accessible by persons with disabilities**

**Target 8.B Establish reliable disability statistics by the midpoint of the Decade, 2017, as the source for tracking progress towards the achievement of the goals and targets in the Incheon Strategy**

The core indicators agreed upon to measure progress in reaching these targets are:

8.1 Disability prevalence based on the International Classification of Functioning, Disability and Health (ICF) by age, sex, race and socioeconomic status

8.2 Number of Governments in the Asia-Pacific region that have established, by 2017, baseline data for tracking progress towards achievement of the Incheon goals and targets.

8.3 Availability of disaggregated data on women and girls with disabilities in mainstream development programmes and government services, including health, and sexual and reproductive health, programmes.

The desirability for evidence based data for targeted policy implementation together with the aim of providing intra national and international comparability is leading to a convergence of disability measurement practices.

The module on child functioning and disability developed by the UN Statistical Commission’s Group on Disability Statistics in association with UNICEF would be incorporated within UNICEF’s Multiple Indicator Cluster Survey (MICS) as the child disability module – that would in turn feed into its annual report on the State of the World’s Children. Before doing so, however, UNICEF needs to test the questions – first via cognitive testing procedures to ascertain whether respondents are interpreting the questions as intended, and then via field tests to determine their workability as a quantitative tool.

Adapt through its Shiksha Sankalp project previously conducted a mapping and screening process within two jurisdictions using a different set of questions. This experience led to many lessons learned, and to the decision to adopt the 12 domain question set as a way forward. The first step in the process was to subject them to cognitive testing. Thus, India and the United States were the first two countries to begin testing these questions. More will follow as part of UNICEF’s initiative to improve disability statistics in the MICS. The cognitive testing process conducted in India is detailed in the following report.
1. **Background:**

The fundamental right to education for all children with disabilities in India was given a constitutional mandate by Parliament in 2010 by the enactment of the Right of Children to Free and Compulsory Education Act (aka RTE). This enactment provides for free and compulsory education for all children age six to fourteen years. Children with disabilities were specifically included within this legislation.

For the first time since independence children with disabilities had the same rights as non-disabled children to access educational services. However, it is acknowledged that millions of children in India are still being denied an education – a significant proportion of them being children with disabilities. In order to address this problem the government needs accurate information not only on the number and whereabouts of these children, but the reasons that are preventing them from attending school.

It was therefore necessary to develop a tested method for locating out of school children, identify their reasons for being out of school, and when these reasons are related to functional difficulties, to assess those difficulties, and link the children to appropriate services so that they enrol and attend school successfully, within the overall protocols of *Sarva Shiksha Abhiyan*[^1] – the national flagship programme for education.

One reason for not attending school may be exclusion on the grounds of social prejudice for SCs, STs OBCs or other minority groups. Other reasons could be that parents desire children to work instead, or that the costs of receiving a quality education are too high, or maybe the lack of proximity to an acceptable school. Some of these reasons are also related to functional difficulties children may have problems in seeing, hearing, walking, fine motor activities, communicating, learning, managing their behaviour, etc.

Some functional difficulties may be mild but may still lead to dropping out of school – for example vision problems correctable by glasses. But some may be more significant and require prolonged therapy, significant adjustments in teaching styles, accessible schools, etc. In order to deploy resources to get children into school as efficiently as possible it is important to get accurate information on their functional difficulties and the environmental barriers they face.

A survey could provide a birds-eye view of these facts but in order to create community networks that can actually reach out to particular children and provide them the services they need, it is important to undertake a complete mapping of out of school children and the reasons for their lack of attendance. This was recognized in the Model Rules under the RTE in Part III, Article 5, which states:

“... the State government/local authority shall undertake school mapping, and identify all children, including children in remote areas, children with disabilities, children belonging to disadvantaged groups, children belonging to weaker sections ...”

[^1]: *Sarva Shiksha Abhiyan*: “Education for All”.
The mapping methodology is a two-step process:

1. **Mapping**: The first stage is a mapping instrument administered to all households to identify out of school children (OOSC) and their reasons for non-attendance:
   a. This instrument is then used on OOSC to find out their stated reasons for non-attendance and also to identify those who are experiencing difficulties in 12 core functional domains that impede their access to education.

2. **Assessment/Screening**: Children thus identified will be sent to a second stage follow-up assessment facility for more detailed assessment of their difficulties and for identifying services that could help them to attend school:
   a. Information will be collected and sent to State officials in a form that can help them to design and allocate services in a way to address children’s needs more effectively.

The second stage assessment will also determine which children were incorrectly identified as having a disability – that is, children who were “false positives.” Basically, the first stage casts a broad net to determine children who appear to be having functional difficulties, and the second stage identifies which of these children truly are disabled, and links them with services appropriate to their situation.

Given the size and scale in the country, care has been taken to try and make the methodology as streamlined as possible so that it can be replicated in a sustainable manner across the country using local capacity.

This set of questions is designed as a first-stage instrument for identifying children with disabilities. They were developed by an international team of experts working with the UN Statistical Commission’s Group on Disability Statistics and UNICEF. The questions are intended to identify children who have difficulties undertaking activities in a core set of functional domains, which would indicate that they are at a higher risk of experiencing limited social participation. In the proposed field study, these children would then be sent to a more detailed second stage assessment in order to determine the exact nature of their disability, if they indeed do have one.

The two-stage nature of this identification is extremely important. It means that “false positives” (child without any disabilities being identified as having some difficulty) are less of a concern than “false negatives” (a child with disabilities being identified as having no difficulty.) The purpose of these questions (to be used in the first-stage) is to cast a broad enough net to capture the vast majority of disabled children. False positives can be identified in the second stage. Of course, minimizing false positives will make the procedure more efficient and economical.
2. **Issues for cognitive testing:**

The first step in this process is to cognitively test the core 12 domain functional questions that are to be used as the questions in the first stage. The purpose of cognitive testing is to determine the quality of the questions being asked. That is, are the children identified by these questions actually the children we are intending to identify, or do we think parents are likely to report functional difficulties we do not think are disabling, or, vice versa, neglect to report difficulties that we want to capture.

The questions were cognitively tested in Mumbai, India, in September 2012 in both English and Hindi. The results are explained in the following sections, including modifications to the questions that were made in response to findings in the early rounds of testing.

It is important to keep in mind the purpose of cognitive testing, which is to ascertain how respondents are interpreting the questions, formulating their answers, and connecting those answers on to the response categories. It is the **QUESTIONS** which are being examined, not the **CHILDREN**. This is qualitative analysis, so there is no reference to variance or standard errors or being representative of the population. Instead, a cross section of different respondents are asked these survey questions and then probed via a qualitative interview to better understand how they are interpreting and answering the question in order to see if the question is working as intended. Typically, the sample size for such an enterprise starts off with only a few dozen respondents. Additional respondents are added until the various interpretations that are uncovered become repetitive.

The result is to (a) modify questions so that they are better understood, and (b) have a deeper understanding of how the questions are answered, which will inform later analysis of the quantitative data after the survey is administered.

Cognitive testing of questions is now standard operating procedure in the United States and Europe when it comes to survey design, but it has not yet been used in India, or many developing countries. However, about 15 countries were involved in cognitive testing of the WG census questions on disability.\(^5\)

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\(^5\) The 15 countries involved in the cognitive testing of the Short Set questionnaire were: Argentina, Brazil, Democratic Republic of the Congo, Egypt, Gambia, India, Kenya, Lesotho, Mauritius, Mexico, Paraguay, Philippines, United Republic of Tanzania, Uganda and Viet Nam. In addition, these countries were involved in the testing of the extended set of questions on functioning: in the ESCAP region: Cambodia, Kazakhstan, Maldives, Mongolia, Philippines and Sri Lanka – as well as Canada, USA and South Africa – AND The Grenada group consisting of: France, Germany, Italy, Portugal, Spain, Switzerland and the United States of America.

3. **Methodology:**

This section details the methodology, including an overview of cognitive interviewing methodology and methods used for this specific project.

3.1 **Overview of Cognitive Interviewing methodology:**

The aim of cognitive interviewing study is to investigate how well survey questions perform when asked of respondents, that is, if respondents understand the questions according to their intended design and if they can provide accurate answers based on that intent. As a qualitative method, the primary benefit of cognitive interviewing is that it provides rich, contextual insight into the ways in which respondents 1) interpret a question, 2) consider and weigh out relevant aspects of their lives and, finally, 3) formulate a response based on that consideration. As such, cognitive interviewing provides in-depth understanding of the ways in which a question operates, the kind of phenomena that it captures, and how it ultimately serves (or fails) the scientific goal. Findings from a cognitive interviewing project typically lead to recommendations for improving a survey question, or results can be used in post-survey analysis to assist in data interpretation.

Traditionally, cognitive testing is performed by conducting in-depth, semi-structured interviews with a small sample of approximately twenty to forty respondents. The typical interview structure consists of respondents first answering the evaluated question and then answering a series of follow-up probe questions that reveal what respondents were thinking and their rationale for that specific response. In this regard, cognitive interviews unfold within a narrative format and are often personal and, in comparison to traditional survey interviews, are unique to each respondent. Through this semi-structured design, various types of question-response problems, such as interpretive errors or recall accuracy, are uncovered—problems that often go unnoticed in traditional survey interviews. By asking respondents to provide textual verification and the process by which they formulated their answer, elusive errors are revealed.

As a qualitative method, the sample selection for a cognitive testing project is purposive. Respondents are not selected through a random process, but rather are selected for specific characteristics such as gender or race or some other attribute that is relevant to the type of questions being examined. When studying questions designed to identify persons with disabilities, for example, the test sample would likely consist of respondents with a previously known disability and, to discover potential causes of false positive or false negative reporting, some respondents with no known disability. Because of the small sample size, not all social and demographic groups are represented. Analysis of cognitive interviews does not produce generalizable findings in a statistical sense, but rather, provides an explicit exploration of response processes including patterns of interpretation, which could lead to response error.

Analysis of cognitive interviews can be conducted from transcribed interviews or, as is often the case, from interviewer notes. The texts of the interviews (either transcribed materials or interviewer notes) are collated by question so that comparisons can be made systematically across all respondents. Several levels of analysis can typically be performed. First, distinct occurrences in which respondents experience difficulty or confusion while answering are identified. Additionally, specific instances or patterns of error are also noted and, most importantly, the particular causes of
those errors are identified. In addition to response errors, analysis of cognitive interviews can be conducted to reveal patterns of question interpretation. By comparing each respondent’s interpretation to a particular question, patterns can be identified and then examined for consistency and degree of variation among respondents. This type of interpretive analysis does not necessarily illustrate overt response errors, but rather provides deeper insight into the substance or the actual meaning that constitutes the survey data.

3.2 Methodology for the present Cognitive Interviewing Study of Proposed Survey Questions for Identifying Out of School Children with Disabilities in India:

The workshop focused on the description of the current state of measuring disability for international comparison; where the absence of a core definition and standards for producing data, a comparable measure and lack of knowledge about how to measure disability made comparison difficult. This had led to the formation by the UN of the a city based Group on Disability Statistics to promote and coordinate international cooperation in the area of health statistics, and to develop a measure within a framework of the ICF model and ensure cultural comparison.

It was further seen that often countries used the census as a measure to find the prevalence of the disabled, with a limited number of questions focusing on specific disabilities. These questions were influenced by their nature, the culture and criteria of a country with respect to considering someone ‘disabled’; which would lead to inaccurate results. Such methodological issues were addressed by the Washington group, where questions developed (based on the ICF Model) were based on functional difficulties because of an underlying health problem, with a continuum of response patterns unlike a dichotomous pattern, to ensure precision of responses.

The issue of difficulty in measuring disabilities in children, due to the different distribution of disabilities in adults and children was discussed, and to provide comparable cross national data these questions were prepared with consultation form various experts (such as survey statistician, paediatricians, speech therapists, developmental psychologists etc...) and were intended for children in the age range of 2-17 years. These questions were based on functional difficulties, with reference to the child’s cohort and were asked to the parents or the primary caregivers, with a continuous pattern of responses.

To understand and validate these questions, the process of cognitive testing was explained to the participants and carried out by them. Cognitive testing and cognitive interviewing are qualitative methods, to examine if the respondent answered the question as intended to elicit a response, and gain an insight into the potential response errors, patterns and socio-cultural factors which influence the respondent’s processing of the question.

The original language of the questionnaire was English. Given the diverse nature of the languages spoken in Mumbai, it was seen that most respondents would experience some discomfort with English due to their lack of familiarity with the language. Therefore, the need for a translation in the local language was felt. Hindi was chosen as it is the national language as well as being easily understood by a majority of the population in Mumbai.
Thus the questionnaire was translated in Hindi initially by using an online translator to obtain a preliminary translated tool.

After the initial translation, the questionnaire was reviewed by the participants before using it for cognitive interviewing. It was seen that there were errors with respect to syntax and grammatical errors, which would lead to misinterpretation of the questions. Furthermore, the dialect of Hindi was academic rather than vernacular in nature, which would make the question difficult to understand for common people. Thus for an easier understanding of the questionnaire the questionnaire was re-translated in the local dialect of Hindi by the participants in the cognitive training workshop. A series of practice sessions highlighted various issues such as an inability to accurately understand some questions due to the lack of concrete examples. This resulted in the second round cultural adaptations discussion with the experts, which involved the inclusion of culture specific concrete activities. Thus, the final questionnaire (with both the versions-English and Hindi) was formed and cognitively tested.

Study period: The cognitive testing was conducted during September 2012 over a seven day period in Mumbai and overseen by the National Center for Health Statistics (NCHS).

Training and orientation provided by Kristen Miller and Mitch Loeb: Training covered a period of 7 days and included an overview of the work and experience of the UN Statistical Commission’s Group on Disability Statistics in terms of developing sets of disability questions for the general population for use on censuses and surveys – and more specifically the work currently underway by the UN Statistical Commission’s Group on Disability Statistics in association with UNICEF on the development of a module designed for the child/youth sub-population. Following the presentation of this background material the remainder of the training workshop was devoted to the question evaluation methodology as proposed by the UN Statistical Commission’s Group on Disability Statistics. Topics included: background to question evaluation, how to conduct a cognitive interview, a mixed-methods approach to question evaluation that included both qualitative and quantitative methods, issues of sampling, taking notes, analysis, report writing and the use of software developed by the NCHS – Q notes. The workshop included the opportunity for participants to test their new skills through practice interviews and real interviews.

Description of the number of interviews: The process of cognitive testing begun with 24 practice interviews followed by 72 interviews with the real respondents. This exercise of practice interviews was a useful one as it enabled the participants to acquaint themselves with the process, address any clarifications which may arise with respect to the nature of the questions and the procedure of probing. This process yielded some useful insights which assisted in the cultural adaptation of the questions to the context in India.

Where interviews were conducted: All the interviews were conducted at ADAPT’s Bandra Centre in Mumbai.

Length of interviews: Each interview was on average of one hour duration. The range was from 1 hour to 3 hours in the case of 4 interviews.

How respondents were recruited: Discussions on selection of the respondents began a month prior to the workshops. Numerous email and skype discussions were held with the Resource persons and in house staff prior to selecting the final list of the respondents. Based on feedback from the trainers it was decided to have one practice interview and three real interviews. For the practice interviews
parents of students enrolled at the ADAPT\(^7\) Bandra center were contacted and requested for their participation. For the real respondents’ parents of the Colaba center, Dharavi center, rural outreach program under the Shiksha Sankalp project and skills development center were contacted for participation. For the parents of ADAPT centers the respective Heads got in touch with the parents and explained the aim of the workshop to them prior to registering them as respondents. It was decided to have as respondents’ parents of children with different types of disabilities and therefore schools or centers providing services to children with hearing impairment, visual impairment and learning disabilities were contacted for their participation. A similar methodology of informing the organization the objective of the workshop was undertaken. None of the organizations providing services to children with visual impairment were able to participate. Parents of children with hearing impairments from the Sanskardham School and Cheshire home willingly participated as respondents.

In all there were 96 respondents, 24 were practice respondents and 72 were real respondents. The breakup of the respondents is as follows; 24 parents from the Bandra center participated as the practice respondents. Parents of students from ADAPT centers participated in the following numbers; 10 from Colaba center, 4 from the Skills development center, 12 from the Pelhar center and 14 from the Dharavi centers. Four external organizations participated as real respondents from where there were 5 parents of children with learning difficulties, 10 parents from Sankardham and 10 parents from Cheshire home and 7 parents from SEC day school participated real respondents. Four personal friends of staff participated as blinded parents of non disabled children.

**Selection of Interviewers:** In view of training master trainers from a cross section of individuals a large pool of ADAPT partners were contacted to participate in the Cognitive testing exercise. An attempt was made to contact participants working across different disability areas. The government agencies working in the area of disability identification as part of their mandate were also contacted. Government agencies working directly in the area of disability identification were also invited for the workshop. Under the Right to Education act the local authorities under the Sarva Shiksha Abhiyan are required to undertake an annual mapping exercise to identify disability whereas the anganwadi worker (community workers) from the Integrated Child Development scheme are also required to do disability identification and therefore these two agencies were invited to participate in the workshop.

ADAPT being the first organization to test this questionnaire in India it was decided to have a group of ADAPT staff attend the workshop. When selecting ADAPT staff, again a cross section of staff was selected namely teaching staff, training staff and therapy staff from across the four centers of ADAPT.

Attendance to all five training days was made mandatory and only those who were able to participate on all the days were permitted to register.

At ADAPT the community workers from the community project and the Shiksha Sankalp project routinely use the WHO 10 point tool as an on going tool to identify children with disabilities in the community. There were discussions to enrol a few of the community workers for the workshop but

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\(^7\) ADAPT has four centres in Mumbai: At Bandra, Chembur, Colaba and Dharavi and a rural centre at Pelhar
due to the logistic difficulties of translations and back translations they were not included as participants.

3.3 Method of analysis:

Analysis of interviews involves data reduction and theory building (i.e. drawing conclusions). Miller et al (forthcoming), for example, explain that analysis of cognitive interviews involves synthesis and reduction. This process can be conceptualized within five incremental steps:

1) Conducting interviews, collecting the ways in which a respondent interpreted and formulated answers to the survey questions,
2) Synthesizing interview text into summaries, detailing how each respondent formulated their answers, including events or experiences considered as well as any difficulties answering the question,
3) Comparing summaries across respondents to identify common themes and to develop a theoretical schema that details phenomena captured,
4) Comparing those themes across subgroups to identify ways in which different groups may process questions differently depending on their differing experiences and socio-cultural backgrounds,
5) Making conclusions based on the theoretical schema that depicts how each question performs as well as providing explanation for the performance.

Consistent with this model, summary notes were generated from interviews. Summary notes were then entered into Q-Notes, a data entry and analysis software application developed by the US National Center for Health Statistics. The summary notes specified the way in which individual respondents answered every survey question, including each respondent’s interpretation of questions and key terms, activities and experiences considered by respondents, and any response difficulties and errors. Next, analysis was conducted systematically across interviews, identifying interpretive patterns (including patterns of response errors) across interviews. Findings from this second level of analysis depict the phenomena captured by each question and allows for the assessment of construct validity.

Use of Q-Notes, ensured a systematic and transparent analysis across all cognitive interviews as well as providing an audit trail depicting the way in which findings are generated from the raw interview data. Without such an analysis, conclusions presented in cognitive interview reports can, without the reader’s knowledge, consist of anecdotal reports derived from one or two standout interviews or the general impressions of interviewers.

Experts at NCHS delivered the training on Q-Notes in Mumbai, and also supervised the data entry and reviewed all the analysis.

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4. **Testing the questions: Question by Question Review**

The question-by-question review gives us an insight into the different types of response patterns observed during the process of cognitive testing. It also assists in understanding the process of the changes in questions and the resulting response patterns, thereby facilitating the choice of the appropriate question.

The cognitive testing was conducted in several rounds. After each round the research team conferred to see if there were any major problems in interpretation. When clear problems existed with the questions they were modified to try to rectify these problems prior to the next round. For some questions no modifications were necessary. For example, for “emotions” the question was the same in each round. On the other hand, for “walking” changes needed to be made.

1. **EMOTIONS:**

**Round 1**
Children aged 5-17 years
Compared with children of the same age, how much does (he /she) worry or feel sad? Would you say...
1) The same or less
2) More
3) A lot more

**Round 2**
Children aged 5-17 years
Compared with children of the same age, how much does (he /she) worry or feel sad? Would you say...
1) The same or less
2) More
3) A lot more

**Round 3**
Children aged 5-17 years
Compared with children of the same age, how much does (he /she) worry or feel sad? Would you say...
1) The same or less
2) More
3) A lot more

**Purpose of the Question**
This question attempts to identify children at risk of having a mental health disability. The aim is to identify children who have mental health issues which are significantly interfering with the child’s schooling and social development. This may be a constantly high level of worry, sadness, or anxiety or it may be episodic in nature, but frequent enough and significant enough to make the child at much higher risk of dropping out of school, not participating in family or community life, or even putting themselves at risk of harming themselves. It is not meant to capture the response to a
transitory event that the child can recover from, like the anxiety of taking a school entrance exam or the normal grieving process that accompanies the death of a parent, although such an event could be a trigger of a more pronounced problem with worry or sadness.

**Response Patterns**
The conceptual understanding of worry and sadness as understood by the respondents was through expressed behaviours equated with feelings of worry or sadness. Respondents had equated behaviours expressing emotion—such as making a fuss, thinking too much and asking repeatedly, ability to perform or participate in activities at home or at school, hitting, to explain the concept of the child being worried. Laughing a lot was equated to not being worried. This is observed by the responses below.

One respondent who answered the ‘same or less’ stated “She doesn’t understand the emotion last week her grandmother died & the mother was crying. She just sat—she knew her grandmother is dead but couldn’t show emotion. She cries if mother hits her for just for that moment. She knows if mother has fever—but there are no emotions beyond that.” This respondent understood the question with reference to the child’s expressing socially appropriate emotion at the particular situation to understand the question. Another one who answered the same or less stated “She is an introvert as compared to other children of her age, she does not express her feelings, she is very choosy about friends and opens up only after some interaction.”

Respondents also tended to equate worry with other emotions such as being stubborn, sensitive, upset or afraid, suggesting that perhaps worrying per se is an abstract concept for them, and thus they have tried to explain it in the light of other behaviours and emotions which are associated with worry, but do not necessarily imply it.

With reference to the comparison clause, it was seen that a majority of parents were unable to compare to other children, and have answered based on the child’s experiences in specific situations such as home, school, or play, or across a variety of situations.

An important feature to note is, some were unable to compare their child to other children, but to explain worry made references to the child’s behaviour in his own timeline, as seen by the following respondent’s response. The respondent answered ‘The same or less,’ and stated “He used to worry about money issues at home. E.g., when friends used to pay school or tuition fees on time & his payment of fees was delayed because his father’s salary came in late. But now everything is fine & he doesn’t worry about anything. He is a cheerful & easy-going boy, who never feels sad during normal times.” Another respondent answered ‘The same or less’ and stated that her son was a jolly boy, he always took efforts to make others and himself happy. Previously he used to get angry but currently he has become very caring For example: if his mom is angry or upset he indicates with a smile or tends to ignore. He feels happy with family but feels sad with outsiders, he feels lonely in school as there is a lot of age difference. Here in the same answer, the respondent is referring to the child’s own timeline, expression of emotion that is interpreted as worry as well as situations and reasons where the child expresses certain emotions.

**Response Problems**
Though a majority of respondents were able to quantify the child’s worry, for some respondents, due to the differing nature of their child’s disability, quantification by the given categories was difficult. For one respondent who was unable to give answer with respect to the categories given stated “For everything else I keep him happy. He is only sad about the fact that he cannot walk, and
sometimes exclaims ‘if only I could walk’... how can I compare this sadness of him being unable to walk to that of other children who are able to walk?’ The respondent feels that the nature of sadness and worry would be different in the case of her child and other children and thus could not be compared. Another respondent who answered ‘Not at all’ stated “The child cannot feel any emotions at all. She laughs all the time without reason. She only cries when hungry or in pain. Otherwise she doesn’t feel anything. When pressed by the interviewer of her reaction when she is playing with something and that thing is taken away from her, the respondent mentioned that she wouldn’t mind and would will just sit rocking her body.” This suggests that the nature of the child’s disability may perhaps influence the respondent’s perception of the child’s worry. This also shows that non expression of the feelings confuses the respondent about what answer to give for the question.

**Conclusion**
This question is useful for indicating the emotional and behavioural state of the child- an important contributor towards schooling and education. The behaviours which have emerged as themes are useful indicators of the presence of an underlying emotional state of the child which would assist in providing essential resource support, and provide a holistic view of the child with respect to his abilities in the other domains. Since respondents are able to quantify emotions and explain it with reference to other emotions, the current version of the question is recommended, and remains unchanged.

As the purpose of these questions is to work “as a set” to identify children to go to the second stage assessment, the issues parents of children with disabilities had in gauging sadness related to their disability is not a problem because those children will be screened positive based on their other disability and the second stage can take a more detailed look at psychological issues.

The main concern – of false negatives – did not arise, so this question seems adequate.

2. **WALKING:**

The questions in this domain were meant for varying age groups as follows:

**Round 1: Children aged 2-4 years**

3a) Compared with children of the same age, does [he/she] have difficulty walking? Would you say...
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Children aged 5-17 years

3b) Compared with children of the same age, does [he/she] have difficulty walking 500 meters on level ground? (That would be about…. [Insert country specific example]) Would you say... [Read response categories]
1) No difficulty (skip 3c)
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

3c) Compared with children of the same age, does [he/she] have difficulty walking 100 meters on level ground? (That would be about…. [Insert country specific example]) Would you say...
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

**Round 2:** Children aged 2-4 years
3a) Compared with children of the same age, does [he/she] have difficulty walking? Would you say...
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Children aged 5-17 years
3b) Compared with children of the same age, does [he/she] have difficulty walking Half a kilometre (1/2 km) on level ground? 
1) No difficulty (skip 3c)
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

3c) Compared with children of the same age, does [he/she] have difficulty walking 200 steps on level ground? 
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

**Round 3:**
Children aged 2-4 years
3a) Compared with children of the same age, does [he/she] have difficulty walking? Would you say...
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Children aged 5-17 years
3b) Compared with children of the same age, does [he/she] have difficulty walking a short distance? for e.g. across a large room. Would you say...
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

3c) Compared with children of the same age, does [he/she] have difficulty walking a longer distance? For e.g. to a store? Would you say...
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

**Purpose of these Questions**
The purpose of these questions was to identify children with varying degrees of difficulty walking. For children aged 2-4, this meant children whose difficulties created barriers to playing, and
exploring and interacting with their environment and their community in a way that excludes them or impinges on their development. For children aged 5-17, the short distance question is meant to identify children whose level of difficulty in walking (with no assistive devices) would affect their ability to care for themselves and contribute to household chores. The long distance question is meant to identify children who experience difficulties undertaking normal childhood activities outside the home – like attending school, participating in cultural or recreational events, etc. These are children who either need assistance to perform these activities or are incapable – because of their lack of mobility.

Response Patterns
The questions in this domain are used to measure functional difficulties in mobility, specifically walking. It was seen that respondents did not have much difficulty in answering these questions across the age groups; however the reference to distance was subjective and was differently understood by many respondents, which necessitated the need for changing the question to include concrete examples to ensure that the respondents understood it objectively. This will be dealt with in greater detail in the section on Response problems.

To quantify the difficulty in walking the respondents referred to the degree of support (Full support with the use of mobility aids, Partial Support with some dependence on walking aids or parents, No support required—completely independent in walking) required by the child, across various age groups.

Respondents also referred to different activities to explain walking such as sports activities, and activities such as crawling and hopping to explain the severity of difficulty in walking across various age groups, as one respondent mentions to Question 2 “He runs, pushes all children aside jumps. He goes very fast no problem in walking and sometimes falls because he is walking fast. He goes alone to the shops and shows them what he wants. He brings back what is needed from the shops. They give him a sample and he brings the exact ingredient. He does not have any problem with potholes or stairs.”

It must be noted that respondents also used behaviours which were general across many situations or specific to situations to explain the child’s difficulty in walking. Respondents were able to compare the child with other children, and at times also compared the child’s walking pattern at different points in time, as mentioned by one of the respondent who reported that her son, has no difficulty now, but as a kid (5-10 years of age), he had difficulty to walk as he could not maintain his balance due to his hearing impairment. But currently he has no difficulty, he is a karate champion, black belt, he is the 2nd degree black belt champion and 3rd deaf child in India. He also does swimming.

References to the behaviours of the child while walking such as crying, being non-cooperative and the child’s ability to walk being influenced by his/her physical condition were also made by the respondents, as seen by one of the responses, to question 3b “For walking across a room both father & mother have to make him to stand then he is made to walk wearing splints & maximum support for a moment. For standing 15-20mints itself he cries a lot and does not cooperate. It’s hard-work for him & us too. But we do regularly without fail, we expecting that one day he may stand & walk in front of us.”

Response Problems:
Respondents could easily answer the question for the age range of 2-4 years, but had problems understanding the questions for walking in the age group of 5-17 years as the distances measured (500 meters and 100 meters) were an abstract number for them, which were difficult to understand.
This is seen by one of the response patterns, for one of the respondents to questions 3b and 3c, for the age range of 5-17 years.

(Question 3b- 500 meters) On asking why does she say ‘some difficulty’ for the child, the respondent said that last year she walked to ‘Lalbaugcha Raja’. The respondent also mentioned that once she has walked to another deity (Siddhi Vinayak temple) with her grandmother. On probing about going to market, shopping, etc. or any other outings, she informed that she has not tried. Where ever they go, they go by car. But, if something is of her liking then she will do it.

(Question 3c- 100 meters) The respondent felt that the child will have lot of difficulty in walking. On asking why she says so, she said “I feel she will not be able to do that.” On bringing to her notice that she has said she will have only some difficulty in 500 meters and lot of difficulty in 100 meters, she said that she will be able to walk long distance holding hand like she did in those instances. But on her own, she will not be able to walk so much. She walk for 5- 10 mins in vacations. The respondent related her 500 meters walk to 2 instances earlier and felt she will have some difficulty while for 100 meters she thought of her daily activities and skills. There were very few such instances when she had walked so much and she could think of only these two.

Respondents also used the pace of speed, the level of assistance required to explain their difficulty in walking, and the reference to distance was lost. This reference to distance is an important indicator of the severity of the functional limitation in walking (as seen by the Skip pattern provided with the selection of NO difficulty), without which the question does not yield much information.

Another issue to be addressed was the inclusion of a specific example to be understood by all. Considering the diverse nature of the respondents with respect to their educational levels, residence in a rural-semi urban and urban setting, and their access to various facilities such as school, playground, market (In the semi urban and rural areas, the distance between the nearest school and other facilities is much more than in the urban area), having an inclusive example for ‘distance’ would have led to errors in the quantification of difficulty.

Thus in Round 2 the option of the distance of 500 Meters was replaced with half a Kilometre which was relatively easier to understand, and 100 meter was replaced with 200 steps. With these options, it was hoped that the concept of a long and a short distance would become clearer to the participants, as 100 and 500 meters seemed too close in range. During the cognitive testing of these questions, it was seen that respondents were able to understand and visualize the distance, but it was seen that they were often provided examples of their children being able to go to the nearest store or garden, which again introduced an element of subjectivity as the distance was still a measurement, though reduced compared to Round 1. One could not be sure of the respondent’s correct understanding of the long and short distance-whether the difference between long and short was significant enough according to the respondents.

Thus in the third round, keeping in mind the rationale of the questions, the questions were changed with respect to their wordiness and the skip pattern was eliminated. This meant that the

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9 Venue of Lord Ganesh celebrations in Mumbai (where devotees have to walk a long distance for a glimpse)
10 Another name for Lord Ganesh
respondents now had to answer both the questions. There was a concrete example introduced in the question itself to indicate a frame of reference for the distance-long or short, and the reference to the evenness of the ground too was eliminated due to the nature of the examples given. Thus in round three the questions read as:

Compared with children of the same age, does [he/she] have difficulty walking a short distance? for e.g. across a large room. Would you say...
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Compared with children of the same age, does [he/she] have difficulty walking a longer distance? For e.g. to a store? Would you say...
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

These examples have effectively highlighted the conceptual understanding of a long and short distance, and the elimination of the requirement for an even terrain makes it easily understood by respondents in semi urban, rural areas where the terrain is often uneven, thus emphasizing on the distance and not the terrain. It was seen that the respondents were able to answer this question with ease and their responses accurately reflected the child’s difficulties, as references were made to the child’s behavior during walking, and his levels of participation in other activities to corroborate with the functional ability of the child.

Conclusion
Keeping in mind the underlying principle of the question, this domain required modifications in each round to ensure that the response was not influenced by ambiguity of the question. Difficulties in walking can be a contributing factor in limiting access to health care and schooling facilities and is hence an important domain to be probed.

The question in the third round yielded a clear picture of the child’s difficulties as a function of the respondent’s understanding of the question, and the examples used by respondents showed that in its final form, this set of questions worked as hoped. They are recommended for being included

3. **SEEING:**

**Round 1**
Children aged 2-17 years
Does [he/she] wear glasses or contact lenses?
Yes
No
Does [he/she] have difficulty seeing? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Round 2:
Children aged 2-17 years
Does [he/she] wear glasses or contact lenses?
Yes
No

Does [he/she] have difficulty seeing? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Round 3
Children aged 2-17 years
Does [he/she] wear glasses or contact lenses?
Yes
No

Does [he/she] have difficulty seeing? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Purpose of the Question
The purpose of this question was to identify children whose vision problems are interfering with their ability to successfully attend school (for those age 5 and over) and undertake activities appropriate for their age. When a child has access to glasses or contact lenses, it is their corrected vision that is of interest (because they are living their lives with that corrected vision). When glasses or contact lenses are not available, their uncorrected vision is of interest, again because it is with that vision that they are living their lives.

Response Patterns:
This question was easily understood by the respondents. Respondents stated the level of difficulty in seeing by assessing the child’s proficiency and ease in performing various activities such as reading, writing copying from the board, watching TV, recognizing objects, tailoring.
This is illustrated in one of the responses given:

The respondent answered No difficulty and stated, “He copies correctly what is being written on the board. He also enjoys watching TV without any problem. His teacher has also never complained of things like he is not able to see or not able to copy from the board.”

It was interesting to see that some respondents mentioned the need for glasses as felt by the doctors after a thorough check-up, while some on the other hand did not feel that the child needed glasses because he was doing just fine, as seen by the two different responses below:

One of the respondents who stated No difficulty mentioned, as a child when her daughter’s eyes began to water, they had taken her to the doctor who suggested a medical check-up in Sion hospital to rule out vision difficulties, which suggested that there were no problems with her vision and her condition of watering eyes was treated. This suggests that the respondents understanding of the need for glasses was guided by medical needs.

Comparing this to another response, where the respondent whose child does not wear glasses feels that the child can see clearly as her eyesight is normal, no eye test were required and feels there is no difficulty at all in seeing - so glasses are not required. This shows that the child’s difficulty is seen through the respondent’s frame of reference of the child’s ability which is subjective in nature. However the nature of such responses was minimal, and at this point it would be important to add that the response here is influenced by the respondent’s views of difficulties in seeing, and not because of the question per se.

Respondents were likely to explain the child’s need for glasses with respect to the child’s behaviour across various situations, and references were also made to the child’s abilities before and after wearing glasses, as seen by a respondent of a child with glasses, who answers 2–3 months after she (the child) was born she underwent a cataract surgery. Even after the surgery she was unable to see things which were close by and so was advised by the doctor to wear glasses. The respondent feels that now she can see clearly without any difficulty with the glasses on, as she can read the alphabet; tell the colours, animals, etc. with the glasses on. This response pattern clearly elucidates the points mentioned in the above.

Response problems
However, a small number of respondents misinterpreted the question where the concept of glasses was equated with wearing sunglasses and answered the question; however such a pattern can be treated as an aberration as most of the respondents were able to accurately understand the question. This difference in response has occurred because of the respondent’s subjective conceptualization of the “glasses”, and is not influenced by the question itself.

Conclusion:
Parents used difficulty in appropriate activities to gauge if their children had vision problems, the primary one being school activities, which was reflected in the child’s performance in school. Thus it is recommended that these questions be included.

One concern is that mild vision difficulties for children of preschool age will not be identified by parents because at that age they are not affecting the child’s activities. This is not a major concern because presumably these children will be identified when they start attending school and start
having problems. Prior to school, their vision difficulties may not be interfering much with their development.

Overall, though, this question performed well.

4. **HEARING:**

**Round 1**
Children aged 2-17 years
Does [he/she] use a hearing aid?
   1) Yes
   2) No

Does [he/she] have difficulty hearing? Would you say… [Read response categories]
   1) No difficulty
   2) Some difficulty
   3) A lot of difficulty
   4) Cannot do at all

**Round 2**
Children aged 2-17 years
Does [he/she] use a hearing aid?
   1) Yes
   2) No

Does [he/she] have difficulty hearing? Would you say… [Read response categories]
   1) No difficulty
   2) Some difficulty
   3) A lot of difficulty
   4) Cannot do at all

**Round 3**
Children aged 2-17 years
Does [he/she] use a hearing aid?
   1) Yes
   2) No

Does [he/she] have difficulty hearing? Would you say… [Read response categories]
   1) No difficulty
   2) Some difficulty
   3) A lot of difficulty
   4) Cannot do at all

**Purpose of the Question**
The purpose of this question was to identify children whose hearing problems are interfering with their ability to successfully attend school (for those age 5 and over) and undertake activities appropriate for their age, including communicating with others. When a child has access to a
hearing aid, it is their amplified hearing that is of interest (because they are living their lives with that hearing). When hearing aids are not available, their unamplified hearing is of interest, again because it is with that hearing that they are living their lives.

**Response patterns**

This too was an easy question for the respondents to understand and the pattern of response was the same as observed for the domain of seeing. The respondents used the activities such as responding to sound, listening to what is being told, and dependence on lip reading as an indicator of the child’s difficulty in hearing. This is seen in the following response given by one of the respondents whose child uses a hearing aid and experiences a lot of difficulty despite using it.

The respondent reported, that her son at birth had intact hearing, but due to jaundice, there was overdose of antibiotics, his hearing was lost the doctor told them it was a life threatening situation. The respondent reported that, he doesn’t benefit much from the hearing aid, as he has difficulty in processing. He does not respond to sound at all in larger areas, like public places, huge halls. She further reported, that he responds only to his name, and few words like mamma, papa. After listening, to his name, he does lip reading and reacts. She also said that if anyone calls him when he is looking down or from back, he does not respond. She said, in class, he needs one to one attention, as he does not understand if too many things are said at a time. Communication is his biggest barrier. Further she reported, that his class teacher has told her, he does a lot of day dreaming, and needs to really shaken to get his attention in class, which could be because of his processing difficulty and deafness. This pattern of responses effectively highlights the points mentioned above, and also shows that the respondent had also used the child’s pre and post behaviour as a frame of reference, and the examples given are both general across many situations and are specific in nature.

It was also seen, that like seeing, the need for a hearing aid was also influenced by a medical need, the child’s condition, or the respondent’s assumption that the child was just fine and did not need a hearing. This is effectively illustrated by the response pattern seen below, where one of the respondents who answers No Difficulty states;

“We have got his ears tested and it showed that there is no problem. When asked if he follows all the instructions, the mother said that depends on his will. He has autism; so sometimes he does sometimes he does not. He listens to music and he can sit even for 2 hrs. About his studies, if asked options, he selects the right one. If we ask him if wants to go by taxi or train he tells us his option...that is taxi. We ask him orally and he answers by pointing.” The respondent added that they have got medical check up done and gave lot of examples to show that her son can hear and has no difficulty in that.

**Response problems**

As an aberration, one of the respondents mistook hearing aid for a Walkman, and answered accordingly, however as mentioned, it was influenced by the respondents understanding and conceptualization of a “hearing machine” and did not reflect a problem with the wording of the question.
Conclusion:
Any difficulties in hearing will impact the child’s performance in school, and thus it is important that any difficulties in this domain be addressed. Parents understanding of the question was very much in line with its intent, thus these questions should be a part of the questionnaire.

5. **PLAYING:**
The questions in this domain were meant for varying age groups as follows:

**Round 1:**
Children aged 2-5 years

Compared with children of the same age, does [he/she] have difficulty playing with toys or household objects?

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Children aged 2-12 years
Compared with children of the same age, does [he/she] have difficulty playing with other children?

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Children aged 13-17 years
Compared with children of the same age, does [he/she] have difficulty doing things with other children? (Include things that children usually do together.) Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

**Round 2**
Children aged 2-5 years

Compared with children of the same age, does [he/she] have difficulty playing with toys or household objects?

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all
Children aged 2-12 years
Compared with children of the same age, does [he/she] have difficulty playing with other children?
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Children aged 13-17 years
Compared with children of the same age, does [he/she] have difficulty doing things with other children? (Include things that children usually do together, like playing Cricket, snakes & ladders, carom, marbles, etc...) Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

**Round 3**
Children aged 2-5 years
Compared with children of the same age, does [he/she] have difficulty playing with toys or household objects?
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Children aged 2-12 years
Compared with children of the same age, does [he/she] have difficulty playing with other children?
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Children aged 13-17 years
Compared with children of the same age, does [he/she] have difficulty doing things with other children? (Include things that children usually do together, like playing Cricket, snakes & ladders, carom, marbles, etc...) Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

**Purpose of the Questions**
Playing is a primary way in which children learn – both about their physical world and their social world. Impairments in any domain can affect playing – vision, hearing, psychological, fine or gross
motor skills, or cognition – depending on the environment. This question is meant to capture a difficulty in playing that is related to any impairment. In fact, it could be that multiple minor impairments might combine to create a more significant barrier to playing. This question is meant to capture difficulties in playing that are linked to any type of impairment, but not to things unrelated to impairments, like “the child has no time to play because she has too many household chores to do”

Response patterns:
The respondents had tried to explain the child’s difficulty in play by referring to the activities which the child indulged in (both indoor and outdoor), and replaced play with other non-play related activities such as to explain difficulty in playing, across all age groups. One of the respondents mentioned that the child had some difficulty as she played well with her toys and with her sister and other cousins. When it comes to standing and walking she is unable to do it. Here she tries to emphasize on the child’s difficulty in standing and feels that being able to stand and walk is also an important indicator for playing.

The respondents also viewed the ability to ability to play/ doing other things being influenced by the child’s condition, and other children’s’ attitudes, behaviours, views and interests towards the child. The knowledge of the child’s difficulty was also influenced by the respondent’s knowledge of the child. This is seen in the following response given by a respondent whose child experiences a lot of difficulty in playing;

“He cannot play any physical activity because of his CP. While playing carom he is not able to give the right strike like others and cheats sometimes because people don’t play with him then. In cricket he cannot run or even stand properly so does not plays that game. He is best in puzzles and loves that game. He also likes phone games and watching T.V programs.”

One of the respondents mentioned that the child experienced some difficulty in playing because “Other kids get bored to play with him e.g. every time they have to pick up the ball & give it to him.” This response highlights how the attitude of other children has influenced the respondents view about the child’s ability to play.

Similarly, respondents also equated playing and doing things together with getting along with others/ mixing, being an active participant, being a passive participant or observer. It is important to note that playing was often used as an indicator of the social relations a child shared with other children, and in that sense, even being a passive observer was considered as a point worth mentioning during responding to suggest that the child even though physically was unable to play, psychologically he was involved in the process by being a passive observer. This is seen by one of the responses given below, where the respondent feels that the child has No difficulties in playing, mentions;

“He can sit and play. In school, he takes part in all competition. He has many certificates. He can play cricket with callipers. He tells others that he can bat and bowl but he can’t run. He also sits and plays badminton. “

Reference was also made to the child’s temperament and emotions to understand the concept of play, and to behaviours which were both generalized and situation specific, with comparison to
other children of the same age, as seen in one of the response patterns given where the respondent feels that the child has a lot of difficulty mentions, “He does not mix at all with other children. When we see children from balcony, tell him ‘let’s go and play’ and we take him down, but he does not go. He does not play in school.”

**Response problems:**
To make the administration uniform, the concrete examples were added to the questions for the ease of the respondent’s understanding and to increase the objectivity of the question. Thus the question which earlier read as;

Compared with children of the same age, does [he/she] have difficulty doing things with other children? (Include things that children usually do together.) Would you say… [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Was changed to

Compared with children of the same age, does [he/she] have difficulty doing things with other children? (Include things that children usually do together, like playing Cricket, snakes & ladders, carom, marbles, etc...) Would you say… [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

The respondents often equated playing and getting along with each other as seen by the following response, where one of the respondents stated that for the child there was no difficulty in playing with other children, he only had a difficulty till he was introduced, but once an introduction was done, he did not have any difficulties and would invite him/her to play. The respondent added that even when he was hit by anyone in school, unless it was not a major issue; he would ask for the matter to be ignored by reasoning that “he is a child just like I am, so why bother, just leave it!” and would only retaliate when he was injured. According to the teachers reports as well, it was reported that he only playfully hit children and was mischievous, but very helpful in class.

This pattern suggests that getting along with children class and playing are seen in the same light by the respondent, and was also seen with other responses as well.

Respondents often viewed playing as the primary activity as a means to getting along with each other, and relationships with other peers were usually explained in the context of play.

**Conclusion:**
As play is the first and primary form of socialization, it is important to address any difficulties which arise in this domain; this includes the attitudes of others. Even if the child is physically capable of playing but his peers will not include him because of impairment then there is still a barrier to
participation related to his impairment. On the other hand if a child has functional difficulties but still actively plays with his peers (as one respondent is described by his mother) then even though he may have a disability when it comes to walking, he can still actively play with others because of accommodations (e.g., playing badminton while sitting). Thus the questions used in the second round worked as desired and are recommended for use.

6. RELATIONS:

Round 1:
Children aged 5-17 years
Does [he/she] have difficulty getting along with children of his/her age? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Round 2:
Children aged 5-17 years
Does [he/she] have difficulty getting along with children of his/her age? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Round 3:
Children aged 5-17 years
Does [he/she] have difficulty getting along with children of his/her age? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Purpose of Question
This question was intended to identify children with problems socializing with other children that impacts their ability to participate in activities with a social dimension. The most likely reason was because of psychological, behavioural, or cognitive issues, but again the reason is not important as long as it is related some way to a functional impairment.

Response Patterns:
The respondents explained the concept with reference to various activities such as playing with friends, socializing and participation, making friends, children coming over, playing with siblings and family, being friendly and well behaved, sharing, caring and communicating. These patterns were observed across all age groups and are illustrated in the responses given below.
One of the respondents answered that the child did not have difficulties in getting along with others mentioned;

“He so good in holding conversation that the person talking to him gets impressed. He is like a magnet; people get attracted to him on their own. He has many friends in school. In the house, he can’t go out, so there are very few friends. But if friends of my other children come home, then he gets along very well. He entertains guests at home. He gets angry only when other children tease him or when they do not include him in their games.”

References were also made to the child’s condition which may pose a difficulty in forming relations, the child’s temperament, and was influenced by the respondent’s knowledge of the child. This is seen by one of the responses given by a respondent, who answered cannot do at all, and during probing mentioned,

“He does not mix with anyone- neither at school, nor at home. He has no friends. He has never mixed with anyone except one child whom he was friendly with and then my child moved to another class. Otherwise, they might have become friends.”

The patterns of responses were both across general and specific situations, in comparison with other children, and a reference to the child’s behaviour across two different points in time. The response below given by one of the respondents who answered No Difficulty, mentioned that initially when he was 4-5 years old, he was very shy and not social at all. He had handful of friends only. But from past 2-3 years, when he started getting comfortable with school, he became social. Now he attends birthday parties, gets social not only with his age children but also younger and elder ones.

Response problems:
This domain, though deceivingly simple, was often interchanged with playing as an activity, and respondents often answered the difficulty in getting along with others by using playing as the barometer. This was seen by the responses given across all age groups.

Conclusion:
The ability to form relations and get along with others is an important part of the socialization process, and is often facilitated in the school setting. Any difficulties in this process such as feeling neglected or feeling left out from the peer group can result in an increased rate of dropping out from school. Conversely, a lack of pro social behaviour can influence access to school as parents may fear sending their children to school because of inadequate social exposure of coping and dealing with other children. This is commonly seen for those children who are affected by some form of disabilities. These questions are included to give a picture of the child’s ability to engage in pro-social behaviour

Thus, to determine the difficulties a child might face during the process of socialization, the question is recommended.

However, there is some concern that this question will generate false positives – that is children whose temperament or personality gets in the way of socializing to a degree that is not particularly far from normal, but still seen as a problem by their parents. As mentioned earlier, though, false positives can be caught at the second stage. The degree of false positives can only be determined
through a field test, so it is recommended that this question is included at that stage to determine if the rate of false positives will be high enough to be problematic.

7. **COPING WITH CHANGE:**

**Round 1**
Children aged 5-17 years
Compared with children of the same age, does (he/she) have difficulty accepting change to plans or routine? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

**Round 2**
Children aged 5-17 years
Compared with children of the same age, does (he/she) have difficulty accepting change to plans or routine? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

**Round 3**
Children aged 5-17 years
Compared with children of the same age, does (he/she) have difficulty accepting change to plans or routine? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

**Purpose of Question**
The purpose of this question is to identify children with behavioural, psychological, or cognitive issues that make them very resistant to change. This is not to identify children who at times can be stubborn, but rather to identify those who have significant problems transitioning from one activity to another on a consistent basis to the extent that it undermines their ability to participate in standard childhood activities. Often these children are very reliant upon routines (e.g., autistic children) in order to cope with a world they find highly stressful and difficult to understand.

**Response Patterns:**
This was an interesting question. Respondents showed a consistent pattern of equating plan with routines, and were able answer it from that frame of reference, as seen by the response of one respondent who answered that the child has some difficulty explained,
“If the plan is changed according to him, there is no difficulty. But it goes against his wish, then it is difficult for him to adjust. E.g. if he decides not to go to school, then it is difficult for anyone to make him to go to school but if mother tells him, he listen without any bribe or showing temper. If plan changes suddenly and if it excites him, then its fine but with drastic changes it’s little difficult.” Here the respondent has equated the ‘routine’ activity of going to school as a ‘plan’.

Respondents tried to explain the concept of coping with change with reference to activities at school or at home, along with other activities such as going out for movies, play and self care activities.

Interestingly, factors such as child’s emotional reactions and temperament, preparedness for accepting change, the respondent’s understanding of difficulty and change-influenced the respondent’s view of change and coping with it. This is seen by the following response given by a respondent who answered some difficulty elaborates,

“He loves to stick to a schedule which is pre planned. When sudden change to the program takes place, he is angry and agitated over the same. At the same time he has great understanding. Yesterday he wanted to visit ‘Lalbagh cha Raja’- a Lord Ganesh’s Idol, but we could not make it, he threw a lot of tantrum over the matter but when we all agreed to visit the Lord on coming Wednesday, he readily agreed to the same.

Though the respondent mentions that the child is also very understanding, the respondent here feels that the child’s feeling of anger and agitation is an indicator of difficulties in accepting change.

The responses were made based on observations which were both generalized and specific to the child’s behaviour and one of the responses effectively highlighted the process of the child’s empowerment as seen below.

One of the respondents mentioned that the child could not do it at all as “He is totally dependent on his parents. It is his parents who decide the daily schedule and take him to different places. As such, he does not initiate any action and stick to it.”

Response Problems:
The respondents did not experience any difficulty in understanding the questions, and while answering they were likely to equate plan and routine together; however this connection was a subjective one, and was not influenced by the questions wording and did not influence the accuracy of the response.

Conclusion:
The fact that parents equated difficulty in dealing with change to needing a routine was positive, in that it aligned with the purpose of the question. This question is useful for understanding the child’s ability to cope with transitions and change, an inability for which could seriously affect performance in school if the child is unable to keep pace.

However, some personality types are a bit more resistant to change than others, so some children with some difficulty in this area could very well be false positives. The key is whether the resistance to change and the love of routine is significant enough to impose barriers to participation. It could be that the cut-off for identifying a child with a difficulty in this area should be “a lot of difficulty” and not “some difficulty”. The extent of false positives and guidance on what level of difficulty
should be used to identify children as being disabled can only be determined through the field test. It is recommended, therefore, that this question be included in the field test.

8. **ATTENTION:**

**Round 1**
Children aged 5-17
Compared with children of the same age, does (he/she) have difficulty completing a task? Would you say... [Read response categories]
   1) No difficulty
   2) Some difficulty
   3) A lot of difficulty
   4) Cannot do at all

**Round 2**
Children aged 5-17
Compared with children of the same age, does (he/she) have difficulty completing a task? Would you say... [Read response categories]
   1) No difficulty
   2) Some difficulty
   3) A lot of difficulty
   4) Cannot do at all

**Round 3**
Children aged 5-17
Compared with children of the same age, does (he/she) have difficulty completing a task? Would you say... [Read response categories]
   1) No difficulty
   2) Some difficulty
   3) A lot of difficulty
   4) Cannot do at all

**Purpose of the Question**
The purpose of this question is to identify children have difficulties with maintaining their attention enough to complete a task. Typically, this will be the result of developmental or cognitive disabilities, including Attention Deficit Disorder. The key is that this difficulty is somehow related to a functional impairment of some kind.

**Response patterns**
The respondents understanding of task completion was equated to the ability to pay attention and concentrate, doing as told (work, playing etc.), ability to perform physical activities, performance of routine/daily activities and the ability to finish without any help.

Respondents were also influenced by the view of task completion being influenced by the physical limitations of the child, the capacity of the child to perform, the interest willingness and motivation of the child to perform.
One of the respondents who answered cannot do at all explains, “He does not want to do anything as he has no balance. He cannot carry out simple tasks. He wants to do but cannot.” When probed about non-physical tasks, she said he did not complete them. “He would colour a little and leave the rest. He does not complete any task more due to his physical state. His body does not support him. He feels he should do them. I feel if his body was ok he would be able to complete.” This clearly highlights the influence of the child’s physical limitations affecting the ratings of difficulty.

Another respondent answered some difficulty explains, “He can do all work. If he is doing some work which is within his reach, he completes the task. Like if he has to keep his books back in the school bag, then he has no difficulty but if you ask him to keep things in the cupboard, then he will not be able to do so as he can’t stand and the cupboard shelves are high. He has no difficulty in doing any task within his capacity.” Here the emphasis is clearly on task completion, rather than the child’s capabilities to complete it.

The respondents also used examples of different activities such as school work, art work, household chores, games, and recreation. Comparison to other children was also present. This is seen by one of the responses where the respondent states cannot do at all and explains, “Children of her age can walk, run and play with toys but she cannot do any of those activities because her limbs don’t move.” Here the respondent has equated the child’s inability to move with the child’s inability to complete a task.

Response problems:
Each of the respondents had their own subjective views of understanding the concepts of ‘task’ and ‘task completion’ which have influenced their responses. The rationale of the question is to assess for difficulties in sustaining attention, however, as the respondents have differing views, some respondents have stated that a difficulty is present in task completion because of the physical limitations of the child. A difficulty in task completion due to physical inability need not necessarily imply an attentional deficit. The respondents have answered this question based on the face value by treating the question which emphasises on task completion and not on attention.

Conclusion:
However, an attentional difficulty is an important indicator of the presence of any learning difficulty which impacts the child’s schooling and the quality of education received; and a question measuring this needs to be included. The fact that some children are being captured because of physical difficulties (and not the intended attention problems) is not problematic because these questions are supposed to work “as a set” to identify children to be assessed more completely in the second stage. The key to these questions is to cast a net that captures as many disabled children as possible.

9. LEARNING TO DO NEW THINGS/REMEMBERING:

The questions in this domain were meant for varying age groups as follows:

Round 1
Children aged 2-3 years

Compared with children of the same age, does [he/she] have difficulty learning the names of common objects? Would you say... [Read response categories]
Children aged 3-17 years
Compared with children of the same age, does [he/she] have difficulty learning to do new things? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Children aged 5-17 years
Compared with children of the same age, does [he/she] have difficulty remembering things that they have learned? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Round 2
Children aged 2-3 years
Compared with children of the same age, does [he/she] have difficulty learning the names of common objects? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Children aged 3-17 years
Compared with children of the same age, does [he/she] have difficulty learning to do new things? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Children aged 5-17 years
Compared with children of the same age, does [he/she] have difficulty remembering things that they have learned? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all
Round 3
Children aged 2-3 years
Compared with children of the same age, does [he/she] have difficulty learning the names of common objects? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Children aged 3-17 years
Compared with children of the same age, does [he/she] have difficulty learning to do new things? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Children aged 5-17 years
Compared with children of the same age, does [he/she] have difficulty remembering things that they have learned? Would you say... [Read response categories]
1) No difficulty √
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Purpose of the Questions
The purpose of these questions is to identify children with mental or developmental issues that get in the way of learning – cognition, memory, attention, communication, etc. It is not meant to identify children who cannot learn because they don’t have access to accessible schools or braille books or similar equipment or facilities.

Response Patterns:
Respondents understood learning by equating it with observational learning, repetition of instructions. To explain the concept of learning, they used activities such as academic activities and learning skills across all age groups.

One of the respondents answered some difficulty, and explained, “Compared to children of his age if they understand the concept at the first instance but her child has to be explained at least thrice. He is lazy in studies. Does not like to speak language. He is very good in Maths and likes to do Maths most of the times. Is also very good at picking up activities. Is able to do it once he is made to understand e.g. doing a puzzle if once explained he is able to match 50 other similar components.”

The respondent’s responses about the child’s difficulty were influenced by the child’s physical limitations, and references were made to the child’s capacity and temperament to learn. Comparison was made with children of the same age, siblings and children. One respondent mentioned that the child had a lot of difficulty in learning to do new things, but no difficulty
remembering them. The respondent mentioned that any task which involved the use of hands or feet was difficult for him to perform and he needed to be taught those skills, after which he would slowly learn, and gave an example of teaching him to learn how to eat, where a time table was prepared for him to have his meals at a fixed time and to finish within the given time. The respondent reported of a slight improvement in his eating habits and stated that normal children by this age could ask and eat whatever they wanted to, while he was unable to do so. The respondent also mentioned that he had a sharp memory, and could not comment on the retentive capacity of children of his age as each one differs. When asked to give an example, she mentioned that once she was not at home and he was alone with his grandmother, who could not find where the salt was, and he immediately pointed towards it.

The ability of the respondents to distinguish between learning and remembering was seen in various responses.

Response problem:
Sometimes, the responses were guided by the respondent’s personal expectations such as the one seen below, one respondent who stated that there was some difficulty in teaching the child to write, and to learn how to behave with others till he understood how to do so. Initially as he was taught to write by holding his hand, but now he could do it well. When asked that if these were the issues faced by other children of the same age, she mentioned that they too experienced the same difficulties; and that he was among the few to pass in his class test with flying colours, where most of the students had failed.

Such patterns were seen across the age groups, but were however not guided by the misinterpretation of the question.

Conclusion:
Knowing the retentive and learning abilities of the child is an important indicator of the child’s education and schooling to provide the necessary support in the case of suspected learning disabilities in school -which may lead to irregularities in attendance or the child dropping out from school. Again, the main concern is false positives among children who are reported to have “some difficulty”. Determining the appropriate cut-off for sending the child to the second stage will have to be determined in the field test.

10. SELF CARE:

Round 1
Children aged 5-17 years
Compared with children of the same age, does [he/she] have difficulty with self-care such as feeding or dressing him/herself? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all
Round 2
Children aged 5-17 years
Compared with children of the same age, does [he/she] have difficulty with self-care such as feeding or dressing him/herself? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Round 3
Children aged 5-17 years
Compared with children of the same age, does [he/she] have difficulty with self-care such as feeding or dressing him/herself? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Purpose of the Question
The purpose of this question is to identify children with significant disabilities – in any domain – that interfere with their ability to look after their own basic needs. The “compared with children of the same age” clause is particularly important here because of the different cultural expectations of when a child is capable of doing things like feeding, dressing, and bathing herself

Response Pattern:
The respondents responses to self care were given with reference to the child’s condition, child’s temperament, dependence on other family members, need for assistance.

One respondent who answered Cannot do at all explains, “His hands are ok. He can eat biscuits, but cannot drink water as his hands shake because he is afraid. He tries but it falls. If he eats by himself, half the rice falls. Uses only left hand. Doctors say his right hand is weak. Throws a ball with the left hand, eats biscuits with his left hand. I have to make him wear his clothes. Does not inform when he needs to go to the toilet. I have to clean up. Sometimes, he says, mostly he does not. Maybe he does not feel that he needs to go”. The respondent felt that he did not perhaps associate the sensation with his needing to go and hence was not learning to indicate. He could hold out his arm to wear the shirt and needed help after that.

Another respondent answered some difficulty and explained, “He can eat with a spoon but not with hand, he can wear his clothes but is not able to button himself up because of his left hand affected due to CP. But he is able to wear his T-shirts well.”

This pattern of rating the child’s difficulty in self care by considering the child’s behaviour across the various instances was seen in the responses obtained.

It was also noted, that depending on the respondent’s views of the child’s ability, the ratings are given. This is seen in the following pattern of response, where one respondent mentions A lot of
difficulty and explains, “We do all things for her. Most of the time she keeps her fingers folded. She is not able to do any activity. We feed her. If her mood is good, she eats (mashed food) and if not holds food in mouth and does not listen. She cannot dress herself, her hand movements does not allow her to do any activity. Whatever she want we do for her or help her in doing any activity.” It is clearly seen that the child is unable to perform any of the self care activities, and yet the respondent feels that the child has ‘a lot of difficulty’ instead of answering that the child being unable to do it.

Response Problems:
While responding, some respondents were likely to only restrict themselves to the examples given. However, this was not a consistent pattern, and overall it was seen that the respondents did refer to a variety of other activities as well, as seen from the responses above.

Conclusion:
The ability to perform activities of self care or daily living is an important determinant of the child’s access to education; as children are often out of school due to their inability to perform such activities and their dependence on their caregivers. Knowing the level of dependence a child has will also enable the allocation of the appropriate resource teacher for the child.

11. BEHAVIOR:
The questions in this domain were meant for varying age groups as follows:

Round 1
Children aged 2-4 years
Compared with children of the same age, how much does (he/she) kick, bite or hit other children or adults?
1) The same or less
2) More
3) A lot more

Children aged 5-17 years
Compared with children of the same age, how much difficulty does (he/she) have controlling his/her behaviour? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Round 2
Children aged 2-4 years
Compared with children of the same age, how much does (he/she) kick, bite or hit other children or adults?
1) The same or less
2) More
3) A lot more
Children aged 5-17 years
Compared with children of the same age, how much difficulty does (he/she) have controlling his/her behaviour? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Round 3
Children aged 2-4 years
Compared with children of the same age, how much does (he/she) kick, bite or hit other children or adults?
1) The same or less
2) More
3) A lot more

Children aged 5-17 years
Compared with children of the same age, how much difficulty does (he/she) have controlling his/her behaviour? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Purpose of the Question
The purpose of the question was to identify children with psychological and behavioural problems that make them violent and thus limit their ability to associate with other children in a productive manner.

Response patterns:
The respondents easily understood the question, and were able to explain it with reference to behaviours such as crying, hitting, withdrawal, compliance, impulsivity, hyperactivity, anger.

One of the respondents who answered A lot of difficulty explained, “She makes her body stiff when she doesn’t want to do something. Pulls her hairs and bites her finger. Even two people are holding her, cannot control her. To control her, we make her sit before TV and when she is normal we continue with the things.”

Another respondent answers No difficulty and explains, “He turns very silent when angry, never has any temper-tantrums. Compared to his siblings, or other children of his age, he has always been more peaceable & never had any difficulty controlling his behaviour. In fact he pulls up his older siblings for their out-of-control behaviour at times.”

Thus, respondents have used behavioural patterns to indicate the presence or absence of any difficulty while controlling behaviour, suggesting that the question was understood by them.
Comparison was made to the behaviours of the child across a variety of situations and references were made to the child’s own behaviour across various situations as seen by a respondent who answered no difficulty and explains that behaviour wise the child is a very good boy. “He is a tiger at home but outside he is well-behaved, polite and is never rude. Sometimes his sister and he fights and they also beat each other, but if shouted he keeps quiet. Mother further said that he is one of those, if done a mistake will say sorry and if not done anything will not listen to anybody. He can control his anger if proper explanation is given to him.”

This shows that the concept of behavioural control was seen objectively by most of the respondents who were able to view the child’s behaviour in totality before rating the child’s difficulty.

Response problems:
A small number respondents found it difficult to understand what it meant to control behaviour, which at times influenced their ratings, such as seen in the case of a respondent who answers Some difficulty- “If she doesn’t like her mother talking to someone she will pull her by her hand & take her away. She has no behaviour problem” Here the concept of behaviour is not clearly understood by the respondent, who states that the child has ‘some difficulty’ in controlling behaviour, but does not have a ‘behaviour problem’. The response is guided by the respondent’s view of how the child should behave.

Conclusion:
Behavioural problems can keep a child away from the benefits of schooling and education by interfering with the child’s progress and socialization, and the inclusion of questions assessing the same are necessary for addressing them. There may be some concern with false positives at the “some difficulty” level, but the extent that is an issue needs to be examined through the field test. Once again, though, false positives are not as problematic as false negatives because they can be dealt with in the second stage.

12. COMMUNICATION/COMPREHENSION:
The questions in this domain were meant for varying age groups as follows:

**Round 1**
Children aged 2-4 years
Does [he/she] have difficulty understanding you? Would you say… [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Do you have difficulty understanding what your child wants? Would you say… [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all
Children aged 5-17 years
Compared with children of the same age and using [his/her] usual language, does [he/she] have difficulty understanding other people? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Compared with children of the same age and using [his/her] usual language, does [he/she] have difficulty being understood by other people? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Round 2
Children aged 2-4 years
Does [he/she] have difficulty understanding you? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Do you have difficulty understanding what your child wants? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Children aged 5-17 years
Compared with children of the same age and using [his/her] usual language, does [he/she] have difficulty understanding other people? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Compared with children of the same age and using [his/her] usual language, does [he/she] have difficulty being understood by other people? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all
Round 3
Children aged 2-4 years
Does [he/she] have difficulty understanding you? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Do you have difficulty understanding what your child wants? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Children aged 5-17 years
Compared with children of the same age and using [his/her] usual language, does [he/she] have difficulty understanding other people? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Compared with children of the same age and using [his/her] usual language, does [he/she] have difficulty being understood by other people? Would you say... [Read response categories]
1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Purpose of the Questions
The purpose is to identify children who have difficulty exchanging information with others. That is, being able to understand people who are attempting to communicate things to them, and also being able to make other people understand their thoughts and desires. The only difficulties to be identified are those related to functional difficulties in communication and cognition – not, for example, because they speak a different language or because they come from a different culture.

Response patterns:
Reference was made to the pattern of difficulty in communication with respect to the following:

   a) Understood by parents but not others
   b) Understood by family
   c) Understood by friends
   d) Understood by teachers
   e) Influenced by child’s condition
Since children are exposed to various languages at home, and in school, reference to the diversity of languages such as one’s mother tongue and the language used in school and society was also made while assessing the difficulty in communication. This is seen by the following response pattern:

One of the respondents mentioned No difficulty for being able to understand the child and states, “I understand him. He shows if he has fever, has a cough, wants water or food, through gestures. Shows that he wants to play with his hands says ‘papa’ if he wants his father. Does not indicate toilet.” The respondent was very sure that she understood every need of the child and unsure whether others would understand him as well. She was the primary caregiver and there was very little occasion for the rest of the family to understand all his needs. This shows that the respondent has made a distinction between the child being understood by the primary caregivers and the others around. Such a pattern was seen in the other responses as well.

The distinction between the rating the difficulty as understanding other people and being understood is highlighted in the response below:

One of the respondents had the question – ‘Compared with children of the same age and using [his/her] usual language, does [he/she] have difficulty understanding other people’ repeated twice as the respondent was unable to comprehend whether the question referred towards understanding others or being understood by them.

The respondent then answered some difficulty and mentioned that he was more comfortable with his mother tongue, and at times if people asked him in a language which he knew but was not comfortable with, he would wait for his mother to translate and then respond. The respondent also added that this was the case with children of the same age as well, as sometimes they too needed an explanation, but the ratio was different. According to the respondent if normal children needed to be explained 30% of the time and children like the child required an explanation 70% of the time, the important point to consider was that BOTH needed an explanation. The respondent also added that at times the ratio could be reversed where normal children would require more explanation, or at times the ratio could be equal, and added that she would now try to make her child comfortable with languages other than the mother tongue.

This pattern of understanding and being understood often required the respondents to think and try to understand the question before replying.

Response problems:
Some respondents would often confuse the child’s difficulty in understanding with the child being understood by others, and the question would require repetitions for their understanding. The question intends to measure the child’s ability to effectively communicate, and understand others, however, the use of the term ‘usual language’ is a source of confusion as the respondents do not know which language-the mother tongue or the one in school or society is to be used as a term for reference. Respondents also conceptualized language as something verbal in nature, which at times could have influenced their difficulty ratings for the child. It was also seen that the term “what your child wants” was subjectively interpreted by respondents and they considered the child’s gesturing as a mode of communication at times.
Conclusion:
However, difficulties in communication and comprehension could impact the child’s ability to benefit from learning, and thus is important to assess them with the help of the given questions.

The question for younger children seemed to work better. The questions for older children were a bit problematic, and the wording may need to be reconsidered. At the very least, the interviewer training needs to highlight the problems with this question and how to respond to interviewees who have difficulties with it.
5. Version recommended for the Field Test:

The following annexures set out the sequence of the cognitive testing process. The first annexure is the 12 domain tool proposed by the UN GDS together with NCHS interview guide leading up to annexure 5 which is the full set proposed for field testing. Preamble questions for the purpose of identifying out of school children and other subject related data are set out in the full set of basic and core domain questions.

5.1 Annexure 1: The original proposed 12 domain questions with NCHS interview guide.
5.2 Annexure 2: The original translated version in Hindi
5.3 Annexure 3: Preamble question for field test
5.4 Annexure 4: Full set (cognitively tested) in English for field test
5.5 Annexure 5: Full set (cognitively tested) in Hindi for field test
6. **Conclusions/Recommendations:**

Overall, the cognitive testing procedure was successful. A research team was trained on cognitive testing procedures, and how to conduct analysis of the results using Q-Notes. The team conducted a large number of interviews – in both English and Hindi – to determine whether the questions tested worked as intended. The questions were designed to identify children with functional difficulties who have a high probability of being disabled.

The testing revealed that the questions performed well. In a couple domains, significant problems of misinterpretation were uncovered in early rounds which led to their modification. In general, respondents were identifying the type of children the instrument is designed to locate, with possibly a tendency for over-identification in the behavioural domains.

Cognitive testing also revealed that the wording of the questions must be adapted to particular languages and cultural environments. It is not adequate to simply translate questions into other languages. They must then be cognitively tested in the each language before being rolled out. However, cognitive testing is not expensive.

Also since the proposed procedure is a first stage to screen for children who are at high risk of having a disability, followed by a second stage to more accurately assess their functioning and link them to services, a tendency towards false positives in the first stage screening instrument is much better than a tendency to false negatives. False positives can be weeded out in the second stage.

However, two key issues remain regarding the proposed two-stage procedure for identifying out of school children with disabilities, namely:

- How extensive will the false positives be? Although theoretically they pose no problem, logistically the procedure will be more efficient and economical if they can be minimized.
- What prevalence will these questions uncover? This is important information for designing the logistics dealing with the second stage as the procedure is rolled out across the population

These issues can only be addressed with a field test. It is essential that a field test be done in order to determine if the rate of false positives is considered acceptable. If not, the questions might need to be modified. The field test is also needed to test the second stage instrument and the coordination of stage one and stage 2 activities.

The field test will validate a mapping/screening tool and an assessment process for mapping OOSC and connecting them to neighbourhood schools with evidence-based targeted support. This process could then be rolled-out for mapping in the country.
INTERVIEWER NAME: ________________________________

Respondent number: ________________________________

Date: ____________________________

INSTRUCTIONS TO INTERVIEWER:

- Introduce yourself
- Explain the purpose of the project
- Make sure the respondent understands that we are testing the questions so that we can develop a good questionnaire
- We need to make sure that everyone understands these questions and that everyone understands them the same way
- Explain the process: that you will ask the questions as if you were an interviewer at their homes, and they will answer the questions. But then you will have more questions to ask you about how you interpreted the questions and came up with your response.
- Ask the respondent if they have any questions

PREAMBLE (interviewer read): The next questions ask about difficulties your child may have in doing certain activities...

SEEING

Children aged 2-17 years

1a) Does [he/she] wear glasses or contact lenses?

1) Yes
2) No

1b) Does [he/she] have difficulty seeing [if (1a) is Yes], when wearing his/her glasses?

Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

HEARING

Children aged 2-17 years

2a) Does [he/she] use a hearing aid?

1) Yes
2) No
2b) Does [he/she] have difficulty hearing [if (2a) is Yes], when using his/her hearing aid(s)? Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

WALKING

Children aged 2-4 years

3a) Compared with children of the same age, does [he/she] have difficulty walking? Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Children aged 5-17 years

3b) Compared with children of the same age, does [he/she] have difficulty walking 500 meters on level ground? (That would be about.... [Insert country specific example]) Would you say... [Read response categories]

1) No difficulty (skip 3c)
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

3c) Compared with children of the same age, does [he/she] have difficulty walking 100 meters on level ground? (That would be about.... [Insert country specific example]) Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

SELF-CARE

Children aged 5-17 years

4) Compared with children of the same age, does [he/she] have difficulty with self-care such as feeding or dressing him/herself? Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

COMMUNICATION/COMPREHENSION
Children aged 2-4 years

5a) Does [he/she] have difficulty understanding you? Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

6a) Do you have difficulty understanding what your child wants? Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Children aged 5-17 years

5b) Compared with children of the same age and using [his/her] usual language, does [he/she] have difficulty understanding other people? Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

6b) Compared with children of the same age and using [his/her] usual language, does [he/she] have difficulty being understood by other people? Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

LEARNING

Children aged 2-3 years

7a) Compared with children of the same age, does [he/she] have difficulty learning the names of common objects? Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all
Original proposed 12 domain questionnaire with NCHS interview guide   Annexure 1

7b) Compared with children of the same age, does [he/she] have difficulty learning to do new things? Would you say... [Read response categories]

   1) No difficulty
   2) Some difficulty
   3) A lot of difficulty
   4) Cannot do at all

Children aged 5-17 years

8) Compared with children of the same age, does [he/she] have difficulty remembering things that they have learned? Would you say... [Read response categories]

   1) No difficulty
   2) Some difficulty
   3) A lot of difficulty
   4) Cannot do at all

EMOTIONS

Children aged 5-17

9) Compared with children of the same age, how much does (he/she) worry or feel sad? Would you say... [Read response categories]

   1) The same or less
   2) More
   3) A lot more

BEHAVIOUR

Children aged 2-4 years

10) Compared with children of the same age, how much does (he/she) kick, bite or hit other children or adults?

   1) The same or less
   2) More
   3) A lot more

Children aged 5-17 years (Age group to be determined through cognitive testing.)

10) Compared with children of the same age, how much difficulty does (he/she) have controlling his/her behaviour? Would you say... [Read response categories]

   1) No difficulty
   2) Some difficulty
   3) A lot of difficulty
   4) Cannot do at all

ATTENTION
Children aged 5-17

11) Compared with children of the same age, does (he/she) have difficulty completing a task? Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

COPING WITH CHANGE

Children aged 5-17 years

12) Compared with children of the same age, does (he/she) have difficulty accepting change to plans or routine? Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

RELATIONSHIPS

Children aged 5-17 years

13) Does [he/she] have difficulty getting along with children of his/her age? Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

PLAYING

Children aged 2-5 years

14 a1) Compared with children of the same age, does [he/she] have difficulty playing with toys or household objects?

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Children aged 2-12 years
Original proposed 12 domain questionnaire with NCHS interview guide  Annexure 1

14a2) Compared with children of the same age, does [he/she] have difficulty playing with other children?

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Children aged 13-17 years

14b) Compared with children of the same age, does [he/she] have difficulty doing things with other children? (Include things that children usually do together.) Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all
शास्त्रकार्यां का नाम : ________________________________

प्रतिवादी का क्रमांक : ______________

तिथि :

शास्त्रकार्यां को आदेश :

• अपनी पेशवान कार्यां
• प्रोजेक्ट का उद्देश्य सामाजिक
• प्रतिवादी को सामाजिक कि हम यह प्रश्न एक आचे प्रश्नात्मक बनाए के सिया जांच रहे हैं
• हमें देखना चाहिए कि सबको प्रश्न समझ आये और एकही तरीके से समझ आये
• प्रक्रम समझ : कि आप प्रश्न ऐसे पूछें जैसे कि वे अपने घर में हो, पर आप और भी प्रश्न पूछेंगे जिसे पता चले कि आप उसका वर्णन कैसे करेंगे
• प्रतिवादियों से पूछें कि उनके पास कोई सवाल हैं
1. ओ वर्ष के नीचे कितने बच्चे इस घर में रहते हैं ______

2. उनके क्या नाम हैं?
   बच्चा #1: ________________
   बच्चा #2: ________________
   बच्चा #3: ________________
   बच्चा #4: ________________

3. क्या उम्र है [name]?
   बच्चा #1: ________________
   बच्चा #2: ________________
   बच्चा #3: ________________
   बच्चा #4: ________________

4. क्या वह स्कूल जाते हैं?
   हां - आग़े बच्चे के पास जाये
   ना - आग़े आग़ा श्रन पर जाये

5. स्कूल क्यों नहीं जाता /जाती?
   (पढ़ें और जाँच लें कि सभी लागू होते हैं)

का इसलिये हैं:

1. बहुत छोटा हैं
2. क्या स्कूल जाना मुश्किल हैं
3. सिख नाही र रहे
4. शिक्षा उसके लिए उपयोगी नहीं
5. शिक्षक उसको पाठना नहीं चाहते
6. शिक्षक उस जैसे बच्चो को पाठा नहीं पा रहे
7. किमत व्यय दर है
8. बच्चे को काम पर जाना है
9. और कुछ : [विवरण करो]
प्रस्तावना (साक्षात्कारकर्ता पढ़ें): अगले प्रश्न कठिनाइयों के बारे में पूछने के अपने बच्चे को कुछ गतिविधियों को करने में हो सकता है ...

देखना

2 से 17 कर उम्र के बच्चे

1a) [वह / वह] चश्मे या कॉन्टेक्ट लेने में पहनते हैं?
   1) हाँ
   2) नहीं

1b) क्या [वह / वह] कठिनाई होती है देखकर [अगर (1 ए) हाँ, जब उसकी / उसके चश्मा पहन रखा है? क्या आप बोलेगे ...]
   1) कोई कठिनाई
   2) कुछ कठिनाई
   3) कठिनाई का एक बहुत
   4) सभी पर नहीं कर सकते

सुनना

2 से 17 कर उम्र के बच्चे

2a) क्या [वह / वह] एक सुनवाई सहायता का उपयोग करें?
   1) हाँ
   2) नहीं

2b) क्या उसको सुनने में दिक्कत हैं, जब वह मशीन लगाता है
   1) कोई कठिनाई
   2) कुछ कठिनाई
   3) कठिनाई का एक बहुत
   4) सभी पर नहीं कर सकते

चलना

2 से 17 कर उम्र के बच्चे

एक ही उम के बच्चों के साथ तुलना करता है, [वह / वह] चलने में कठिनाई है? आप क्या कहेंगे...
   1) कोई कठिनाई
   2) कुछ कठिनाई
   3) कठिनाई का एक बहुत
   4) सभी पर नहीं कर सकते
५ से १७ साल के उमर के बच्चे

3b) उसके उमर के बच्चों कि तुलना में, क्या उसको ५०० मीटर चलने में दिक्कत है (यह कुछ ऐसे हैं .... का आप बोलने....)
   1) कोई कठिनाई
   2) कुछ कठिनाई
   3) कठिनाई का एक बहुत
   4) सभी पर नहीं कर सकते

3c) उसके उमर के बच्चों कि तुलना में, क्या उसको १०० मीटर जामीन पर चलने में दिक्कत है क्या आप कहेंगे
   1) कोई कठिनाई
   2) कुछ कठिनाई
   3) कठिनाई का एक बहुत
   4) सभी पर नहीं कर सकते

खुद कि देख बाल

५ से १७ साल के उमर के बच्चे

4) उसके उमर के बच्चों की तुलना में, क्या उसको खुद कि देखकर चरणों में दिक्कत है क्या आप कहेंगे
   1) कोई कठिनाई
   2) कुछ कठिनाई
   3) कठिनाई का एक बहुत
   4) सभी पर नहीं कर सकते

संपर्क / समझ

२ से ४ साल के उमर के बच्चे

5a) क्या [यह / वह] तुम्हें समझने में कठिनाई होती है?आप क्या कहेंगे ...
   1) कोई कठिनाई
   2) कुछ कठिनाई
   3) कठिनाई का एक बहुत
   4) सभी पर नहीं कर सकते

6a) क्या आपको अपने बच्चे को समझने में दिक्कत हैं ?आप क्या कहेंगी ?
   1) कोई कठिनाई
   2) कुछ कठिनाई
   3) कठिनाई का एक बहुत
   4) सभी पर नहीं कर सकते
5 से 17 साल के बच्चे

5b) एक ही उम्र के बच्चों के साथ तुलना कर रहे हैं और अपने / उसे] सामान्य भाषा का उपयोग करता है, [वह / वह] अन्य लोगों को समझने में कठिनाई होती है? क्या आप कहेंगे?
   1) कोई कठिनाई
   2) कुछ कठिनाई
   3) कठिनाई का एक बहुत
   4) सभी पर नहीं कर सकते

6b) एक ही उम्र के बच्चों के साथ तुलना और [उसकी / उसके] सामान्य भाषा का उपयोग करते हुए, [वह / वह] कठिनाई अन्य लोगों द्वारा समझा जा रहा है? क्या आप कहेंगे?
   1) कोई कठिनाई
   2) कुछ कठिनाई
   3) कठिनाई का एक बहुत
   4) सभी पर नहीं कर सकते

सिखना

2 से 3 के उमर के बच्चे

7a) उसके उमर के बच्चों कि तुलना में, क्या उसको आम चीज़ों के नाम आते हैं? क्या आप कहेंगे?
   1) कोई कठिनाई
   2) कुछ कठिनाई
   3) कठिनाई का एक बहुत
   4) सभी पर नहीं कर सकते

3 से 17 के उमर के बच्चे

7b) उसके उमर के बच्चों कि तुलना में, क्या उसको नयी चीज़ों को करणे में दिक्कत हैं? क्या आप कहेंगे?
   1) कोई कठिनाई
   2) कुछ कठिनाई
   3) कठिनाई का एक बहुत
   4) सभी पर नहीं कर सकते

5 से 17 साल के बच्चे

8) उसके उमर के बच्चों कि तुलना में, क्या उसको सिखी हुई चीज आड़ आती है? क्या आप कहेंगे?
   1) कोई कठिनाई
   2) कुछ कठिनाई
   3) कठिनाई का एक बहुत
   4) सभी पर नहीं कर सकते
भावना

५ से १७ साल के उमर के बच्चे

9) उसके उमर के बच्चों कि तुलना में, क्या वह भावूक हैं क्या आप कहेंगे
   1) कम या वही
   2) ज्यादा
   3) बहुत ज्यादा

बतौर

२ से ४ साल के बच्चे

10) उसके उमर के बच्चों कि तुलना में, क्या वह दुसरों को लाभ,काटता और मारता हैं क्या आप कहेंगे
   1) कम या वही
   2) ज्यादा
   3) बहुत ज्यादा

५ से १७ साल के बच्चे

10) उसके उमर के बच्चों कि तुलना में, क्या वह आपने बतौर को रोकता हैं क्या आप कहेंगे
   1) कोई कठिनाई
   2) कुछ कठिनाई
   3) कठिनाई का एक बहुत
   4) सभी पर नहीं कर सकते

सावधान स्थिति

५ से १७ साल के बच्चे

11) उसके उमर के बच्चों कि तुलना में, क्या वह आपने कार्य पूर्ण करता हैं क्या आप कहेंगे
   1) कोई कठिनाई
   2) कुछ कठिनाई
   3) कठिनाई का एक बहुत
   4) सभी पर नहीं कर सकते

बदलाव का सामना

५ से १७ साल के बच्चे

12) उसके उमर के बच्चों कि तुलना में, क्या उसे परीक्षणी में बदलाव आच्छा लागता हैं क्या आप कहेंगे
   1) कोई कठिनाई
   2) कुछ कठिनाई
   3) कठिनाई का एक बहुत
   4) सभी पर नहीं कर सकते


संबंध

५ से १७ साल के बच्चे

13) क्या उसको दूसरे बच्चो से मेल मिलाप में दिक्कत हैं
   1) कोई कठिनाई
   2) कुछ कठिनाई
   3) कठिनाई का एक बहुत
   4) सभी पर नहीं कर सकते

खेलना

२ से ५ साल के बच्चे

14 a1) उसके उमर के बच्चो कि तुलना में, क्या उसे खिलाओने से खेलने में दिक्कत हैं क्या आप कहेंगे
   1) कोई कठिनाई
   2) कुछ कठिनाई
   3) कठिनाई का एक बहुत
   4) सभी पर नहीं कर सकते

२ से १२ साल के बच्चे

14a2) उसके उमर के बच्चो कि तुलना में, क्या उसे दूसरे बच्चो के साथ खेलने में दिक्कत हैं क्या आप कहेंगे
   1) कोई कठिनाई
   2) कुछ कठिनाई
   3) कठिनाई का एक बहुत
   4) सभी पर नहीं कर सकते

१३ से १७ साल के बच्चे

14b) उसके उमर के बच्चो कि तुलना में, क्या उसे दूसरे बच्चो के साथ मिलकर काम करना अच्छा लगता हैं क्या आप कहेंगे
   1) कोई कठिनाई
   2) कुछ कठिनाई
   3) कठिनाई का एक बहुत
   4) सभी पर नहीं कर सकते
### Part I: INTERVIEWER INSTRUCTIONS:

#### INTERVIEWER NAME: ______________________________

#### INSTRUCTIONS TO INTERVIEWER:

- Introduce yourself
- Explain the purpose of the project

“As you may know a law has been passed in 2010 under which ALL children in India have the right to FREE and COMPULSORY education for 8 years from 6 to 14 years.

We are trying to find out HOW many children are not going to school so that such children can be helped to go to school.

To do this we want to find out what difficulties children may have that might prevent them from attending school.”

**ASK FOR HOUSEWIFE / MAIN EARNER / ADULT AGED 25 YEARS + OF THE FAMILY ONLY OTHERWISE REVISIT LATER**

### Part II: RESPONDENT DETAILS

**Respondent number & name: ______________________________**

**Religion: ______________________________**

**Caste / Tribe:**

- [ ] SC
- [ ] ST
- [ ] OBC
- [ ] Others, Please specify ______________________________

**Economic Status: BPL**

- [ ] EWS (Economically Weaker Section)

**Others, Please specify ______________________________**

**Language of Interview: ______________________________**

**Date: ______________________________**
Part III: CHILD’S DETAILS IN HOUSEHOLD

Good Morning / Afternoon! We are conducting a study on Children who are Not in School on behalf of the Ministry of Human Resource Development (MHRD). Can I ask you a few questions please?

1. How many children in the age group 6 to 14 years live in this household? _______

2. Their information

<table>
<thead>
<tr>
<th>Sr. No.</th>
<th>Name</th>
<th>Boy=1; Girl=2</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
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<td></td>
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<td>5</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If no children then go to END.
If more than one child, repeat next section for each child.

3. How often did [Name] attend school this year?
   - Often or always   Go to next child
   - Sometimes
   - Never
   - Don’t Know

4. Has [Name] dropped out of school?
   - Yes
   - No
   - Don’t Know

5. Why does [Name] not attend school? (Read and check all that apply)

Is it because:
   a. Too young
   b. Too difficult to get to school
   c. Not able to learn
   d. Child will not be able to use education
   e. Teachers do not want to teach him/her
   f. Teachers are not able to teach children like him/her
   g. Costs too much
   h. Child has to work
   i. Child has to look after family members
   j. Other: [specify]

□

□

□
Implementing the Right of Children to Free and Compulsory Education

MINISTRY OF HUMAN RESOURCE DEVELOPMENT (MHRD), NEW DELHI, INDIA

Identifying Out of School (OOS) Children in the age group 3 to 14 years

With special focus on Children with Functional Difficulties (CFD)

A FIELD STUDY ADMINISTERED BY AC NIELSEN
Part I: INTERVIEWER INSTRUCTIONS:

INTERVIEWER NAME: __________________________________

INSTRUCTIONS TO INTERVIEWER:

- Introduce yourself
- Explain the purpose of the project

“As you may know a law has been passed in 2010 under which ALL children in India have the right to FREE and COMPULSORY education for 8 years from 6 to 14 years.

We are trying to find out HOW many children are not going to school so that such children can be helped to go to school.

To do this we want to find out what difficulties children may have that might prevent them from attending school.”

ASK FOR HOUSEWIFE / MAIN EARNER / ADULT AGED 25 YEARS + OF THE FAMILY ONLY OTHERWISE REVISIT LATER

Part II: RESPONDENT DETAILS

Respondent number & name: ______________________________

Religion: ________________________

Caste / Tribe:

☐ SC ☐ ST ☐ ☐ OBC

☐ Others, Please specify ________________________________

Economic Status: BPL EWS (Economically Weaker Section)

Others, Please specify ________________________________

Language of Interview: ____________________________

Date: _____________________________
Part III: CHILD’S DETAILS IN HOUSEHOLD

Good Morning / Afternoon! We are conducting a study on Children who are Not in School on behalf of the Ministry of Human Resource Development (MHRD). Can I ask you a few questions please?

1. How many children in the age group 6 to 14 years live in this household? _______

2. Their information

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If no children then go to END.
If more than one child, repeat next section for each child.

3. How often did [Name] attend school this year?
   - Often or always   Go to next child
   - Sometimes
   - Never
   - Don’t Know

4. Has [Name] dropped out of school?
   - Yes
   - No
   - Don’t Know

5. Why does [Name] not attend school? (Read and check all that apply)
   
   Is it because:
   a. Too young
   b. Too difficult to get to school
   c. Not able to learn
   d. Child will not be able to use education
   e. Teachers do not want to teach him/her
   f. Teachers are not able to teach children like him/her
   g. Costs too much
   h. Child has to work
   i. Child has to look after family members
   j. Other: [specify]

   □

   □

   □

Identifying Out of School Children age group 3 to 14 yrs
With special focus on Children with Functional Difficulties (CFD)
Part IV: FUNCTIONAL DOMAIN QUESTIONNAIRE

PREAMBLE (interviewer read): The next questions ask about difficulties your child may have in doing certain activities...

DOMAIN 1: SEEING

Children aged 2-17 years

1a) Does [he/she] wear glasses or contact lenses?
   1) Yes
   2) No

1b) Does [he/she] have difficulty seeing [if (1a) is Yes], when wearing his/her glasses? Would you say... [Read response categories]
   1) No difficulty
   2) Some difficulty
   3) A lot of difficulty
   4) Cannot do at all

DOMAIN 2: HEARING

Children aged 2-17 years

2a) Does [he/she] use a hearing aid?
   1) Yes
   2) No

2b) Does [he/she] have difficulty hearing [if (2a) is Yes], when using his/her hearing aid(s)? Would you say... [Read response categories]
   1) No difficulty
   2) Some difficulty
   3) A lot of difficulty
   4) Cannot do at all

DOMAIN 3: WALKING

Children aged 2-4 years

3a) Compared with children of the same age, does [he/she] have difficulty walking? Would you say... [Read response categories]
   1) No difficulty
   2) Some difficulty
   3) A lot of difficulty
   4) Cannot do at all
Children aged 5-17 years

3b) Compared with children of the same age, does [he/she] have difficulty walking a short distance? (That would be say for e.g. across a large room. [Insert country specific example]) Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

3c) Compared with children of the same age, does [he/she] have difficulty walking a longer distance? For e.g. to a store? (That would be about.... [Insert country specific example]) Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

**DOMAIN 4: SELF-CARE**

Children aged 5-17 years

4) Compared with children of the same age, does [he/she] have difficulty with self-care such as feeding or dressing him/herself? Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

**DOMAIN 5: COMMUNICATION/COMPREHENSION**

Children aged 2-4 years

5a) Does [he/she] have difficulty understanding you? Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

6a) Do you have difficulty understanding what your child wants? Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all
Full set in English for field test

Annexure 4

Identifying Out of School Children age group 3 to 14 yrs

Children aged 5-17 years

5b) Compared with children of the same age and using [his/her] usual language, does [he/she] have difficulty understanding other people? Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

6b) Compared with children of the same age and using [his/her] usual language, does [he/she] have difficulty being understood by other people? Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

DOMAIN 6: LEARNING

Children aged 2-3 years

7a) Compared with children of the same age, does [he/she] have difficulty learning the names of common objects? Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Children aged 3-17 years

7b) Compared with children of the same age, does [he/she] have difficulty learning to do new things? Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Children aged 5-17 years

8) Compared with children of the same age, does [he/she] have difficulty remembering things that they have learned? Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all
Full set in English for field test

DOMAINE 7: EMOTIONS

Children aged 5-17

9) Compared with children of the same age, how much does (he/she) worry or feel sad? Would you say... [Read response categories]

1) The same or less
2) More
3) A lot more

DOMAIN 8: BEHAVIOUR

Children aged 2-4 years

10) Compared with children of the same age, how much does (he/she) kick, bite or hit other children or adults?

1) The same or less
2) More
3) A lot more

Children aged 5-17 years (Age group to be determined through cognitive testing.)

10) Compared with children of the same age, how much difficulty does (he/she) have controlling his/her behaviour? Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

DOMAIN 9: ATTENTION

Children aged 5-17

11) Compared with children of the same age, does (he/she) have difficulty completing a task? Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

DOMAIN 10: COPING WITH CHANGE

Children aged 5-17 years

12) Compared with children of the same age, does (he/she) have difficulty accepting change to plans or routine? Would you say... [Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

**DOMAIN 11: RELATIONSHIPS**

Children aged 5-17 years

13) Does [he/she] have difficulty getting along with children of his/her age? Would you say...

[Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

**DOMAIN 12: PLAYING**

Children aged 2-5 years

14 a1) Compared with children of the same age, does [he/she] have difficulty playing with toys or household objects?

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Children aged 2-12 years

14 a2) Compared with children of the same age, does [he/she] have difficulty playing with other children?

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

Children aged 13-17 years

14 b) Compared with children of the same age, does [he/she] have difficulty doing things with other children? (Include things that children usually do together, like playing Cricket, snakes & ladders, carom, marbles, etc...) Would you say...

[Read response categories]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all
साक्षात्कर्ता का नाम:______________________________

माता/पिता का क्रमांक:___________

तिथि:

साक्षात्कर्ता को आदेश:

• अपनी पेहचान कराए

• प्रोजेक्ट का उद्देश्य समझाए

• माता/पिता को समझाए कि हम यह प्रश्नावली एक अच्छी प्रश्नावली बनाने का प्रयास कर रहे हैं।

• माता/पिता से पूछे कि/क्या उनके मन में कोई सवाल है?

• हमें दिखाना चाहते हैं कि सब ये प्रश्न एक ही तरह से समझे

• प्रक्रिया: आप प्रश्नावली के सवाल पूछेंगे और वे जवाब देंगे उसके बाद आप उनसे और सवाल पूछेंगे.
1. १८ साल के कम उम्र के कितने बच्चे इस घर में रहते हैं ______

2. उनके क्या नाम है?
   बच्चा # 1: __________
   बच्चा # 2: __________
   बच्चा # 3: __________
   बच्चा # 4: __________

3. क्या उमर है? (नाम के साथ)
   बच्चा # 1: __________
   बच्चा # 2: __________
   बच्चा # 3: __________
   बच्चा # 4: __________

4. क्या [नाम] वह स्कूल जाते हैं?
   हां - अगले बच्चे के पर जाये
   ना - अगल प्रश्न पर जाये

5. स्कूल क्यों नहीं जाता / जाती?
   (पढ़े और जहाँ भी लागू होते हैं, उसपर चिन्ह लगाए) क्या इसलिया है : क्योंकि
   1. बहुत छोटा है
   2. स्कूल जाना मुश्किल है
   3. सिख नहीं पाते
   4. शिक्षा उसके लिये उपयोगी नहीं
   5. शिक्षक उसको पढाना नहीं पाते
   6. शिक्षक उस जैसे बच्चों को पढ़ा नहीं पा रहे
   7. खर्च ज्यादा है
   8. बच्चे को काम पर जाना है
   9. और कुछ : [विवरण करे]
Full set in Hindi for field test

आप पढ़े : अगले कुछ प्रश्न बच्चों कि क्रिया करने में कोई कठिनाई आती है उनके बारे में है।

देखना

[२ से १६] के उम्र के बच्चे

१a) क्या वह चश्मा / ऐंकल या कॉन्टेक्ट लेन्स पहनता / ती है?
   1) हाँ
   2) नहीं

१b) क्या उसे दिखाई देने में कठिनाई होती है (अगर १ अ हाँ, है) चश्मा / लेन्स पहनने पर भी आपके अनुसार
   1) कोई कठिनाई नहीं
   2) थोड़ी कठिनाई
   3) बहुतज्यादा कठिनाई
   4) बिल्कुल नहीं कर पाता

सुनना

[२ से १६] के उम्र के बच्चे

२a) क्या वह सुनने की मशीन / श्रवणयंत्र का उपयोग करता है?
   1) हाँ
   2) ना

२b) क्या उसे सुनने में कठिनाई होती है (अगर २ अ हाँ, है) मशीन / यंत्र लगाने पर भी आपके अनुसार
   1) कोई कठिनाई नहीं
   2) थोड़ी कठिनाई
   3) बहुतज्यादा कठिनाई
   4) बिल्कुल नहीं कर पाता

चलना

[२ से ४] के उम्र के बच्चे

३a) हमउम के बच्चों की तुलना में, क्या उसे चलने में कठिनाई होती है? आपके अनुसार
   1) कोई कठिनाई नहीं
   2) थोड़ी कठिनाई
   3) बहुतज्यादा कठिनाई
   4) बिल्कुल नहीं कर पाता
Full set in Hindi for field test

Annexure 5

[५ से १६] साल के उम्र के बच्चे

३b) हमारे के बच्चों की तुलना में क्या उसको १२ / किमी में सीधी जमीन पर चलने में कठिनाई होती है? (जैसे की पास के मार्केट तक) आपके अनुसार

१) कोई कठिनाई नहीं
२) थोड़ी कठिनाई
३) बहुतज्यादा कठिनाई
४) बिल्कुल नहीं कर पाता

३c) हमारे के बच्चों की तुलना में, क्या उसको २०० कदम सीधी जमीन पर चलने में कठिनाई होती है? (जैसे की अपने घर में घूमना) आपके अनुसार

१) कोई कठिनाई नहीं
२) थोड़ी कठिनाई
३) बहुतज्यादा कठिनाई
४) बिल्कुल नहीं कर पाता

खुद कि देखभाल

[५ से १६] साल के उम्र के बच्चे

४) हमारे के बच्चों की तुलना में, क्या उसको खुद कि देखभाल (जैसे खाना, कपड़े पहनना इत्यादि) करने में कठिनाई होती है?

१) कोई कठिनाई नहीं
२) थोड़ी कठिनाई
३) बहुतज्यादा कठिनाई
४) बिल्कुल नहीं कर पाता

संपर्क / समझ

[२ से ४] साल के उम्र के बच्चे

५a) क्या उसे (बच्चे को) आपको समझने में कठिनाई होती है? आपके अनुसार

१) कोई कठिनाई नहीं
२) थोड़ी कठिनाई
३) बहुतज्यादा कठिनाई
४) बिल्कुल नहीं कर पाता
6a) क्या आपको अपने बच्चे कि जस्ते तो समझने में कठिनाई होती है? आपके अनुसार
1) कोई कठिनाई नहीं
2) थोड़ी कठिनाई
3) बहुतज्यादा कठिनाई
4) बिल्कुल नहीं कर पाता

[५ तक १६] साल के बच्चे
5b) हमारे बच्चे कि तुलना में और अपनी रोजमर्रा की भाषा का प्रयोग करने पर, क्या उसे (बच्चे को) दूसरों को समझने में कठिनाई होती है? आपके अनुसार
1) कोई कठिनाई नहीं
2) थोड़ी कठिनाई
3) बहुतज्यादा कठिनाई
4) बिल्कुल नहीं कर पाता

6b) हमारे बच्चे कि तुलना में और अपनी रोजमर्रा की भाषा का प्रयोग करने पर, क्या अन्य लोगों को उसको समझने में कठिनाई होती है? आपके अनुसार
1) कोई कठिनाई नहीं
2) थोड़ी कठिनाई
3) बहुतज्यादा कठिनाई
4) बिल्कुल नहीं कर पाता

सीखना
[२ से ३] के उम्र के बच्चे
7a) हमारे बच्चे कि तुलना में, क्या उसे आम चीजों के नाम सीखने में कठिनाई होती है? आपके अनुसार
1) कोई कठिनाई नहीं
2) थोड़ी कठिनाई
3) बहुतज्यादा कठिनाई
4) बिल्कुल नहीं कर पाता
Identifying Out of School Children age group 3 to 14 yrs
With special focus on Children with Functional Difficulties (CFD)
Full set in Hindi for field test

 Annexure 5

[५ से १५] साल के बच्चे

10) हमारे के बच्चों कि तुलना में, क्या उसको अपने बर्ताव को काबू में रखने के लिए कितनी कठिनाई होती है? आपके अनुसार

1) कोई कठिनाई नहीं
2) थोड़ी कठिनाई
3) बहुत ज्यादा कठिनाई
4) बिल्कुल नहीं कर पाता

सतर्क स्थिति

[५ से १५] साल के बच्चे

11) हमारे के बच्चों कि तुलना में, क्या उसे काम पूरा करने में कठिनाई होती है? आपके अनुसार

1) कोई कठिनाई नहीं
2) थोड़ी कठिनाई
3) बहुत ज्यादा कठिनाई
4) बिल्कुल नहीं कर पाता

बदलाव का सामान

[५ से १५] साल के बच्चे

12) हमारे के बच्चों कि तुलना में, क्या उसे रोजमर्रा के काम या योजना में बदलाव स्वीकार करने में कठिनाई होती है?

आपके अनुसार

1) कोई कठिनाई नहीं
2) थोड़ी कठिनाई
3) बहुत ज्यादा कठिनाई
4) बिल्कुल नहीं कर पाता

संबंध

[५ से १५] साल के बच्चे

13) क्या उसे हमारे वर्तमान के साथ मेलजोल करने में कठिनाई होती है?

1) कोई कठिनाई नहीं
2) थोड़ी कठिनाई
3) बहुत ज्यादा कठिनाई
4) बिल्कुल नहीं कर पाता

Identifying Out of School Children age group 3 to 14 yrs
With special focus on Children with Functional Difficulties (CFD)
खेलना

[२ से ५] साल के बच्चे

१४ a1) हमउम के बच्चों कि तुलना में, क्या उसे खिलौनों या घरेलू खेलों के साथ खेलने में कठिनाई होती है? आपके अनुसार

  1) कोई कठिनाई नहीं
   2) थोड़ी कठिनाई
   3) बहुतज्यादा कठिनाई
   4) बिल्कुल नहीं कर पाता

[२ से १२] साल के बच्चे

[१४ a2] हमउम के बच्चों कि तुलना में, क्या उसे दूसरे बच्चों के साथ खेलने में कठिनाई होती है? आपके अनुसार

  1) कोई कठिनाई नहीं
   2) थोड़ी कठिनाई
   3) बहुतज्यादा कठिनाई
   4) बिल्कुल नहीं कर पाता

[१३ से १६] साल के बच्चे

१४b) हमउम के बच्चों कि तुलना में, क्या उसे दूसरे बच्चों के साथ मिलकर कुछ करने में कठिनाई होती है? (क्रिकेट, सापसीटी, कर्कम, कॉँच इत्यादि) आपके अनुसार

  1) कोई कठिनाई नहीं
   2) थोड़ी कठिनाई
   3) बहुतज्यादा कठिनाई
   4) बिल्कुल नहीं कर पाता