

Q&A from Asha Austin meeting (August 5, 2011)

Folks,

I've consolidated questions from the minutes as well as the ones sent on this thread here. If others have any questions do pose them on this thread.

thanks

-vinod

What is the level of interaction between normal kids and mentally disabled kids at Balwadi / Chennanhalli campus

Shristi runs a balwadi for children under the age of 6, from the villages surrounding Channenhalli, in their rural campus. Initially, the balwadi was aimed at identifying mental disabilities and delayed development syndromes at a very early age, since a lot of medical and behavior training can be done at very early ages than at later ages. Over 3 years of running the program, they have now noticed that the kids who come to the balwadi and now are going to regular schools, are extremely sensitive to kids with mental disabilities and are very cooperative in their dealings with them in school. There is a good bit of interaction between the mentally disabled kids and the balwadi children -- although the balwadi children are quite young.

Inclusive activity is a big component of Shristi's program for each child. Shristi believes that it is very important for the development of the mentally disabled to be able to interact with normal children without prejudice. Shristi is planning to set up an inclusive park for children with or without disabilities to all play together. They believe that such inclusive interaction is a vital component of the overall program for each child.

What does 'work-place behavior' training mean? What is Shristi doing to better equip vocational unit kids for social interactions in external workplace

Work-place behavior training is meant to convey occupational therapy and other training to cultivate socially acceptable behavior in different situations. This therapy/training is a part of each child's program and not necessarily restricted to those in vocational unit. In the context of children with multiple disorders, this training is to help the children cope in regular social settings with multiple sensory input situations -- having dinner in a restaurant, or attending a wedding, for eg. If the children are able to adapt to such situations, its usually quite a respite to the parents.

In the context of the vocational unit children, this training involves how to interact with people, what should be acceptable and what is to be considered as crossing a line, etc. This is also important from child protection perspective -- the mentally handicapped are extremely often targeted for all kinds of abuse, from teasing and mocking to forced actions and rape. So the training is to equip the children in understanding what to expect, how to react, and what is okay and what is not, once they leave the protective and sheltered atmosphere of Shristi.

In the cash balance statement, what is the first line on the left hand side (liabilities) mean? Is it representative of Cash in the bank?

If you are referring to capital funds, I think it is the value of all equipment and other fixed assets at Shristi, vs., any loans (liabilities) against such fixed assets.

Asha SV evaluation sheet on Outreach (slide 57) indicates "it was recommended that govt start using this kit on a larger scale". It also says "support for govt anganwadi programs - understanding use of autism kits". Is the kit being referred to above the same as the STAT kit. If that is the case, it seems a little contrary to the other update about the STAT kit being proprietary and Shristi folks not been qualified to impart training to the others on the kit. Or did i misunderstand the email. Where was the STAT kit developed. There must be some place where training on its usage is being provided. Can we find out more about that and see if KWS / RMKM special educators can get trained there on the use of this kit?

No, the slide is referring to an in-house Autism recognition survey+check-up kit and not STAT. STAT is proprietary and was started by some researchers in Vanderbilt University. You need to be trained and certified to use it, and you need a license to train others in it. Folks keep asking me about this -- so I am including references about screening methods. Do read the abstracts/article for more details. You can always ask me for more information too :)

Some screening instruments rely solely on parent responses to a questionnaire, and some rely on a combination of parent report and observation. Key items on these instruments that appear to differentiate children with autism from other groups before the age of 2 include pointing and pretend play. Screening instruments do not provide individual diagnosis but serve to assess the need for referral for possible diagnosis of Autism. These screening methods may not identify children with mild Autism, such as those with high-functioning autism or Asperger syndrome.

It is definitely possible to connect KWS and RMKM with Shristi and have them discuss screening methodologies and see if that is useful to each or any.

Several screening instruments have been developed to quickly gather information about a child's social and communicative development within medical settings. Among them are the following key ones:

[1] Checklist of Autism in Toddlers (CHAT);

Baird G, Charman T, Baron-Cohen S, Cox A, Swettenham J, Wheelwright S, Drew A. A screening instrument for autism at 18 months of age: A 6-year follow-up study. Journal of the American Academy of Child and Adolescent Psychiatry, 2000; 39: 694-702.

Abstract

OBJECTIVES:

A population of 16,235 children aged 18 months was screened using the Checklist for Autism in Toddlers (CHAT) to identify childhood autism (CA). Two further screening procedures were conducted at age 3 and 5 years. The population was followed up at age 7 years in order to establish the sensitivity, specificity, and positive predictive value of the instrument.

METHOD:

A brief checklist assessing joint attention and pretend play behaviors was administered by primary health care practitioners when the children were 18 months old. Follow-up methods included screening through parents and health practitioners and checking medical and educational records.

RESULTS:

Nineteen cases of CA were successfully identified by the CHAT at 18 months. At follow-up a total of 50 cases of CA were identified via all surveillance methods. Thus, the CHAT has a sensitivity of 38% and a specificity of 98% for identifying CA. The positive predictive value of the instrument was maximized by concentration on the highest-risk group. Repeated screening 1 month later increased the positive predictive value to 75% for identification of CA but reduced the sensitivity to 20%, although the specificity was close to 100%. The screen also identified cases of pervasive developmental disorder as well as children with language and other developmental disorders.

CONCLUSIONS:

The CHAT can be used to identify cases of autism and related pervasive developmental disorders at 18 months of age. It is emphasized that the CHAT is not a diagnostic instrument but can identify potential cases of autism spectrum disorders for a full diagnostic assessment.

[2] Modified Checklist for Autism in Toddlers (M-CHAT);

Robbins DJ, Fein D, Barton MI, Green JA. The modified checklist for autism in toddlers: an initial study investigating the early detection of autism and pervasive developmental disorders. Journal of Autism and Developmental Disorders, 2001; 31(2): 149-151.

Abstract

Autism, a severe disorder of development, is difficult to detect in very young children. However, children who receive early intervention have improved long-term prognoses. The Modified Checklist for Autism in Toddlers (M-CHAT), consisting of 23 yes/no items, was used to screen 1,293 children. Of the 58 children given a diagnostic/developmental evaluation, 39 were diagnosed with a disorder on the autism spectrum. Six items pertaining to social relatedness and communication were found to have the

best discriminability between children diagnosed with and without autism/PDD. Cutoff scores were created for the best items and the total checklist. Results indicate that the M-CHAT is a promising instrument for the early detection of autism.

[3] Screening Tool for Autism in Two-Year-Olds (STAT);

Stone WL, Coonrod EE, Ousley OY. Brief report: screening tool for autism in two-year-olds (STAT): development and preliminary data. Journal of Autism and Developmental Disorders, 2000; 30(6): 607-612.

The Screening Tool for Autism in Two-Year-Olds (STAT; Stone & Ousley, 1997) is an empirically derived measure designed for use by professionals involved in early identification and intervention. Its purpose is to provide a relatively brief interactive measure that can be used by health care workers and other service providers to identify children in need of more extensive and specialized follow-up 608 Stone, Coonrod, and Ousley diagnostic testing. The STAT differs from the CHAT in that it was developed to serve as a second-stage screening, that is, to differentiate children with autism from children with other developmental disorders. In comparison with the CHAT, the STAT contains a wider variety of interactional items, is suitable for a broader age range, and consists entirely of items that do not require language comprehension.

[4] Social Communication Questionnaire (SCQ) (for children 4 years of age and older).

Berument SK, Rutter M, Lord C, Pickles A, Bailey A. Autism Screening Questionnaire: diagnostic validity. British Journal of Psychiatry, 1999; 175: 444-451.

Abstract

BACKGROUND:

Good interview and diagnostic measures for autism and other pervasive developmental disorders (PDDs) are available but there is a lack of a good screening questionnaire.

AIMS:

To develop and test a screening questionnaire based on items in the best available diagnostic interview--the Autism Diagnostic Interview--Revised (ADI-R).

METHOD:

A 40-item scale, the Autism Screening Questionnaire (ASQ), was developed and tested on a sample of 160 individuals with PDD and 40 with non-PDD diagnoses.

RESULTS:

The ASQ has good discriminative validity with respect to the separation of PDD from non-PDD diagnoses at all IQ levels, with a cut-off of 15 proving most effective. The differentiation between autism and other varieties of PDD was weaker.

CONCLUSIONS:

The ASQ is an effective screening questionnaire for PDD.

Has SSA attempted to work with the government for funding support? Are there govt support programs for autism research and activities that SSA can tap into?

Shristi had worked closely with the govt for a variety of funding support. Let me list a few:

(a) They've tapped into govt. grants for 80(G) educational orgs for land/infrastructure. The new Autism center in Nagarbavi is built on govt. granted land.

(b) They register the children as medically diagnosed as mentally handicapped which makes them eligible for a monthly stipend, bus/train passes, and a few other perks. In a few cases, their monthly stipend turns out more than their parents income.

(c) They support govt schemes and anganwadi schemes for the mentally disabled through training and materials.

(d) They participate in scholastic activity (Dept. of Child Welfare conferences) and offer suggestions for structuring the govt. mental homes.

There is very little money allocated by the govt for specific research activities etc. for Autism. Its all rolled into a larger budget dispensed by govt. orgs like ICMR. Problems like leprosy or tuberculosis tend to be more visible and receptive to ICMR funding than Autism.

Can you also make a comment about what is the impact of RTE (if any) on SSA. I think we should have all our project updates include this, and i forgot to ask you this qn previously.

The short answer is that RTE does not have any impact on Shristi. RTE has language (all over the place) specifically providing clauses for "disabled and disadvantaged groups". The disadvantaged are clearly defined as per the schedules (SC/ST/OBC etc.). Disabled is not explicitly defined anywhere and is open for interpretation by each state during its implementation. Clearly this is one of the many open loopholes in the law which will be petitioned for by various activist groups. Kapil Sibal while presenting the RTE bill to the Lok Sabha explicitly said that "disabled" should be interpreted to include physical, speech & hearing, visual, and mental disabilities. It remains to be seen to what extent this will get implemented. Some excerpts from the Lok Sabha discussions on the RTE bill (full text attached) [these suggestions were responded to by Kapil Sibal saying the **disabled clause should include** all this.

- SHRI MOHAMMED E T BASHEER (PONNANI): Sir, I would like to say one thing about special schools. When we talk about education for all, what is the meaning of it? I would like to appeal to the hon. Minister and the Government that ignoring these special schools, physically handicapped, mentally retarded children etc. are not correct. So, I would like to request the hon. Minister to include these particular sections of the society also within the purview of this Act.
- SHRI ARJUN RAM MEGHWAL: I have to put forward some suggestions in regard to this Bill. Let the Central Government come forward to provide cent percent finance on education. Then, the children upto the age of 6 years should also be taken care of under this Bill. Arrangements have to be made for the teachers to teach the children of poor people in the slums/lepers settlements itself. There is a need to open exclusive schools for the retarded, dumb and deaf, physically and mentally challenged children. For this purpose specially trained teachers are required to be deputed. There is also a need to provide scholarships to the children of BPL families and poor people