Q3: What approaches are available to enable non-specialized health care providers to identify children with intellectual disabilities, including intellectual disabilities due to specific causes?

Background

In high income countries an important strategy for early detection and management of intellectual disabilities (ID) has been the integration into health, education and social care systems of developmental monitoring of children (i.e. standardized screening and surveillance) (Ertem et al, 2008). Surveillance of the development of infants and pre-school children can enable the identification of children who have or at risk of developmental disabilities so that early intervention can be targeted to these children (Sonnander 2000). Methods for developmental monitoring of young children by health care providers in low and middle income (LAMI) countries are lacking (Ertem et al, 2008).

Population/Intervention(s)/Comparator/Outcome(s) (PICO)

Population:	children at significant risk of intellectual disabilities
Interventions:	use of screening tools or criteria for identification and assessment
Comparator:	use of no tools or one tool versus other
Outcomes:	appropriate identification and diagnosis

Systematic review commissioned

Robertson J, Hatton C, Emerson E (2009). The identification of children with or at significant risk of intellectual disabilities in low and middle income countries: A review. Lancaster: Centre for Disability Research. (commissioned and received in 2009).

Narrative description of the studies (including study-by-study table)

A total of 38 articles form the basis of the review. The majority of the articles (21) were concerned with the validation of a particular screening test for use in one or more low and middle income (LAMI) countries to identify children with disabilities. A further 8 articles reported primarily prevalence studies which employed a screening test to identify children with disabilities. Three studies looked at alternatives to the use of screening tests to identify children with disabilities (Gona et al 2006; Kuruvilla & Joseph 1999; Thorburn et al, 1991). One article described a screening test (Phatak & Khurana, 1991); one talked about screening in China (Ericsson et al, 2008); one was based on clinical trials involving use of a milestone chart (Scherzer, in press); one was based on field testing a portfolio of assessment and advice materials (Wirz et al, 2005); one evaluated in-service training of anganwadi workers (AWWs) to detect disabilities (Mathur et al, 1995); and one was a review article (Nair & Radhakrishnan, 2004).

*LIC: low income country; LMIC: lower middle income country; UMIC: upper middle income country

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Aina OF, Morankinyo O (2001).	Nigeria	LIC	Daycare centres, nursery schools, immunization clinics, religious centres and home visits in area in South West Nigeria	128 children aged 2-30 months	Validation	Developmental Screening Inventory validated against the Bayley Scales of Infant Development	Reliability based on Cronbach's correlation coefficient was found to be significantly high ($p < 0.01$) at a value of +0.64, and scores of both instruments correlated significantly indicating satisfactory validity.	Conclude that the DSI is important in the early detection of disorders such as specific developmental disorders, pervasive developmental disorders, mental retardation, autism etc. Cheap and easy to use.

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Arya S (1991).	India	LMIC	Rural areas of India	600 children aged 0-6 years of whom 300 assessed by psychologist	Development & validation	National Institute for the Mentally Handicapped Developmental Screening Schedule (NIMH-DSS)	3.2% screened positive, 100% of whom confirmed as having developmental delay. False positive rate 1%; false negative rate 0.8%; sensitivity 0.79; specificity 0.99.	Conclude that the NIMH-DSS is an effective tool for screening pre-school children for ID in rural areas of India.

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Awasthi S, Pande VK (1997).	India	LMIC	Urban slums/32 Anganwadi Centres	811 aged 2-4	Validation	Revised Pre-screening Denver Questionnaire (R-PDQ); 1 in 6 also Denver Development Screening Test	R-PDQ took 19.73 mins; DDST took 22 mins. Some questions were "difficult to interpret" e.g. "pedals tricycle" (no tricycles to pedal); "copies circles" (mother's illiterate, would not have seen them try to copy circle); "gives first and last names" (in slums last names not used by mothers)	R-PDQ had "difficult to interpret" questions, high referral rates for further screening for developmental delay; and bad correlation with DDST. It cannot be used for first stage screening for developmental delay in urban slums of Lucknow, India. DDST may be considered for community screening in urban slums and in places with high levels of maternal illiteracy

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Bashir A et al (2002).	Pakistan	LIC	4 population groups in and around Lahore: rural village; periurban slum; urban slum; and upper middle class.	649 children aged 6-10 yrs who were part of a prospective cohort study	Prevalence study (mild mental retardation (MMR))	Ten Questions Screen (TQS) used in first phase. Second phase assessment by specialist and testing by clinical psychologist with Griffiths Mental Developmental Scales; Harris Good Enough Drawing Test; Urdu translation of the Wechsler Intelligence Scale for Children	Overall prevalence of MMR among 6-10-y-old children was 6.2%. The distribution of MMR was uneven, with 1.2% among children from the upper-middle class, 4.8% in the village, 6.1% in the urban slum and 10.5% in the poor periurban slum area.	The prevalence of MMR was found to be higher in a developing country than in developed countries. It also seemed to be related to poor socioeconomic conditions, as the prevalence in the upper-middle class was comparable to figures from developed countries, while the prevalence in children from poor population groups was much higher.

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Chopra G et al (1999).	India	LMIC	Urban slums of South Delhi	19 AWWs screened 3560 children aged 0-6 years	Development and validation	Disability Screening Schedule (DSS) - a one-time screen for all major disabilities administered by grass root level workers	AWWs received 6 days training. The 19 AWWs screened 3560 children from 9 urban slums. 245 classed as impaired. To validate the screening work 219 of the impaired children were reviewed as well as 536 (16%) of those who screened normal. Sensitivity was 0.89 and specificity was 0.98 which are higher figures than other major screening tests under use. Administration time was about 5 minutes.	One problem reported in using developmental milestones is that parents did not always know exactly how old their child was.

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Christianson AL et al (2002).	South Africa	UMIC	8 villages in socio-economically deprived rural area (Bushbuckridge)	6692 children age 2-9 years from 8 villages	Prevalence study	Ten Questions Screen used in first phase. Paediatric evaluation by clinician and Griffith's Scale of Mental Development in second phase.	Of 6692 2-9 year olds screened with TQS, 722 (10.8%) had paediatric evaluation. ID prevalence was 3.56% (0.64% severe, 2.91% mild).	Factors observed which may be associated with the high rate of mild ID include poor living conditions, malnutrition, limited intellectual stimulation of infants and children, and unattended home births.

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Couper J (2002).	South Africa	UMIC	Isolated rural area in KwaZulu-Natal	2,036 children age 0-9 years screened by 12 community health workers	Prevalence study	TQS adapted with addition of 6 questions to allow use with under 2 year olds. Translated into Zulu. Those positive on screen followed up with professional assessment.	163 screened positive, 158 of whom were followed up. 122 confirmed to have disability. Overall 6% had disability. The most prevalent disabilities were mild perceptual or learning disability (17/1,000), followed by cerebral palsy (10/1,000), hearing loss (10/1,000), moderate to severe perceptual disability (6/1,000) and seizure disorders (4/1,000)	They covered an extensive area in a limited time period and had to cover vast distances by foot. The survey was physically challenging for them. It proved to be a low cost method of screening for children with disabilities. The fact that 6% of rural children are disabled has serious implications for delivery of health, welfare and educational services to these children where resources are limited.

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Durkin MS et al (1994).	Bangladesh, Jamaica Pakistan	2 LICs; 1 UMIC	Community settings in Bangladesh, Jamaica and Pakistan	Phase one 22,125 age 2-9 years; phase two 3,983	Validation	Phase one TQS; Phase two clinical evaluations. In Bangladesh and Pakistan, used nonverbal scales of the Stanford-Binet Intelligence Scales and an adaptive behaviour scale developed for the study, or if they could not be tested with Stanford-Binet, the Denver Developmental Screening Test. Different tests used in Jamaica for 6-9 yr olds and DDST used for 2-5 year olds.	Over 22,000 children screened: 10,299 Bangladesh (8.2% screen positive), 5,461 Jamaica (15.2%), and 6,365 (14.7%) in Pakistan. Sensitivity of the screen for serious cognitive, motor, and seizure disabilities was acceptable (80-100%) in all three populations, whereas the positive predictive values range from 3 to 15%. These results confirm the usefulness of the TQS as a low-cost and rapid screen for these disabilities, although not for vision and hearing disabilities, in populations where few affected children have previously been identified and treated.	The value of the Ten Questions for identifying disability in underserved populations is limited to that of a screen; more thorough evaluations of children screened positive are necessary to distinguish true- from false-positive results and to identify the nature of the disability if present

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Durkin MS et al (1998).	Pakistan	LIC	Greater Karachi, Pakistan	6,365 children age 2-9 yrs	Prevalence study	Phase one TQS. Phase two for screen positives - clinical evaluation including nonverbal scales of the Stanford-Binet intelligence test and an adaptive behaviour scale developed (and normative for) children in Pakistan.	Of 6,365 children screened, 936 (14.7%) screened positive on the TQS. 818 (87%) of these and 545 (10%) who screened negative clinically evaluated in phase 2. Overall prevalence estimates were 18.97/1000 for serious MR and 65.33/1000 for mild MR. Multivariate analyses revealed lack of maternal education was strongly associated with the prevalence of both serious (odds ratio = 3.26, 95% CI 1.26-8.43) and mild (odds ratio = 3.08, 95% CI 1.85-5.14) retardation. Other factors that were independently associated with mental retardation in Karachi included histories of perinatal difficulties, neonatal infections, postnatal brain infections, and traumatic brain injury, as well as current malnourishment.	Using lack of maternal education as an indicator of socioeconomic disadvantage, prevalence rates for both serious and mild MR were associated with low socioeconomic status. Very low %s who had been evaluated or received services or been to school point to need for improved recognition and provision of services for MR in less developed countries

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Durkin MS et al (1995).	Bangladesh, Jamaica, Pakistan	2 LICs; 1 UMIC	Community settings in Bangladesh, Jamaica and Pakistan	22,125 age 2-9 years	Evaluation of reliability and internal structure of TQS	TQS	Using multiple methods of assessing reliability, they found that the TQS is a reliable questionnaire and indicators of reliability are comparable across populations that differ in culture and level of socioeconomic development.	One of the questions appears to "over-identify" children as seriously disabled in Jamaica.

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Ericsson K et al (2008).	China	LMIC	Two screening surveys in 14 counties in eight of China's 30 provinces.	Over 100,000 children aged 0-6 years were screened	Screening surveys	Used the Denver Developmental Screening Test (DDST) as there was a Chinese version standardized in 6 urban areas of China. Those who screened positive given a developmental evaluation using the China Neuropsychological Developmental Scale for Children	Not stated	Used a train the trainer approach to set up around 400 developmental screening teams in 14 counties.

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Ertem IO et al (2008).	Turkey	UMIC	1. University affiliated community based well-child care clinics in Ankara 2. Medical students at University School of Medicine Paediatrics Dept	1. 510 aged 0-24 months. 2. 184 medical students/92 children.	Development, validation, determining ages of attainment of milestones	Guide for Monitoring Child Development (GMCD). A practical one sheet open-ended interview with developmental milestones for 8 age ranges from 0-24 months.	GMCD administered in average of 7 minutes. Item-total scale correlations ranged from 0.28 to 0.91. An age-dependent attainment pattern was seen in all of the milestones. Interrater reliability between medical-student pairs and between a child development specialist and students was high (kappa scores were 0.83–0.88). The sensitivity, specificity, and positive and negative predictive values (based on n=79) were 0.88, 0.93, 0.84, and 0.94, respectively.	The GMCD training program developed by the authors consists of written materials, slides and demonstration videos and has been adopted by the Turkish Ministry and Health and UNICEF-Turkey to be used in a nationwide training program on child development for primary health care providers.

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Gladstone M et al (2008).	Malawi	LIC	Rural area of Southern Malawi with low literacy rates	1st stage piloting 20; 2nd stage piloting 20; standardization 1130 children age 0-6.5 years	Development, validation, standardization	138 item developmental assessment tool created using items from Denver II, DDST and Griffith's by replacing culturally inappropriate items.	Face, content and respondent validity were demonstrated. At a consensus meeting 110 items were retained in the revised instrument. Items not attained by age 6 years came from the Denver II fine motor section (e.g. Draws a square).	In all domains of western tests there are some items which are culturally inappropriate for rural Africa such as prepares cereal, play board games. Children screamed with terror when they saw the pink doll in the DDST kit. They are now refining the tool further with a larger standardization sample and creating a scoring system plus carrying out further validation.

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Gona J et al (2006).	Kenya	LIC	Rural area of Kenya	144 focus group participants	Evaluation of identification method	Participatory rural appraisal (PRA)	237 children with disabilities aged 9 to 15 years identified giving prevalence of 69/1000.	Estimated to cost US$1.20 per child identified compared to between US$7 to US$14 for survey methods
Islam S et al (1993).	Bangladesh	LIC	Community settings in Bangladesh	Phase one: 10,299 age 2-9 years; phase two 1,626	Prevalence and relationship to measures of SES	TQS & scale of SES constructed for study	For mild MR the prevalence in lower SES was nearly three times that in middle or upper SES. The relationship of SES to severe MR was relatively weak and ns.	
Kromberg J et al (2008).	South Africa	UMIC	8 villages randomly selected in socio-economically deprived rural area	6,692 age 2-9 years	Two phase screening to look at prevalence and types of disability. (Also interviews with traditional healers).	Phase one: TQS administered by local field-workers. Phase two: examination and testing by paediatricians with neurodevelopmental expertise	722 (10.8%) had a paediatric assessment. 4.3% had one or more of five selected disabilities. The most common disorder was ID (3.6%). 0.64% had severe ID and 2.92% had mild ID.	

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Kuruvilla S, Joseph A (1999).	India	LMIC	Community setting in rural India	5,968 (all ages including adults)	Comparison of identification methods	House to house survey versus rapid rural appraisal (RRA)	No child under the age of two was identified using either method and children under the age of 5 were only identified if they had a severe disability.	They suggest that a simple screening tool such as the TDSC would be needed for all children under 2 years of age
Lansdown RG et al (1996).	China, India & Thailand	3 x LMICs	Community settings including rural, urban slums & rural tribal	28,139 children age 0-6 years	Development & standardization	Culturally appropriate measures for monitoring child psychosocial development at family and community level for each country.	In each country between 13 and 19 key milestones incorporated into the child's home-based record; between 35 and 67 test items devised in each country to test children at first-referral level	Line drawings used for illiterate families. Study illustrates importance of producing locally based norms e.g. “is able to use a cup” varied from 35.4 months in urban Indian children to 9.5 months in Thailand.

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Malhi P, Singhi P (2002).	India	LMIC	Well-child paediatric outpatient department of tertiary care teaching hospital	79 parent-child dyads (child age 24-60 months)	Evaluation of relationship between parental concern and developmental status	Parents Evaluation of Developmental Status (PEDS); compared with Developmental Profile II & Vineland Social Maturity Scale	Overall, the presence of significant parental concerns identified 61.5% of children with delayed development and 65.2% of children with normal development. The positive predictive value of PEDS was 25.8% and the negative predictive value was 89.6%.	Sensitivity in North American children was 75%, specificity 74% - as both are lower in Indian sample they suggest that PEDS should not be used as an alternative to standardized developmental screening in that setting. They suggest that PEDS may be used as a pre-screening instrument in a busy outpatient setting to identify children who may require more in depth developmental screening. Need to confirm and extend these results with larger sample.

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Malik M et al (2007).	India	LMIC	Urban slum of Delhi	202 infants aged 0-12 months	Screening for psychosocial development	Psychosocial Developmental Screening Test developed by the Indian Council of Medical Research. It looks at 5 areas: gross motor; vision and fine motor; hearing language and concept development; self help skills or personal skills; social skills.	Personal skills, hearing, language and concept development and motor milestones were attained by more than 90% of infants in time. Vision and fine motor and social skills were achieved in time by slightly less.	An objective evaluation of development of infants living in urban slums is necessary for early detection of developmental delay. The research is limited and the results of the present study are not sufficient to plan interventions to improve the development of children in such settings. Further research is needed with larger sample sizes.

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Mather GP et al (1995).	India	LMIC	Anganwadi Centres	1545 children below 6 years of age	Evaluation of training AWWs to detect disability	Inservice training on detecting disability (4 hours a day for 6 days). Screening pro-forma used but unspecified.	Amongst the 1545 children, AWWs identified disability in 126 subjects which were verified in 118 cases by paediatricians. The disability rate was 7638 per 100,000 populations. Visual, mental, orthopaedic, speech and hearing disabilities rates were 4790, 2654, 583, 518 and 453 per 100,000 population, respectively	Doctors from dept of paediatrics visited each centre to help AWWs with the survey and provide measures to prevent handicaps (including immunization, supplementary nutrition, and iron to anaemic children, vitamin A or D in those with deficiency).
Mung'ala-Odera V et al (2004).	Kenya	LIC	Community settings in poor rural area of Kenya	Phase one 10,218 age 6-9 years. Phase two 810 screen positives, 766 screen negatives	Validation study	TQS administered by field workers and evaluation by clinician and psychologist for phase two	Sensitivity ranged from 0.70-1.00; specificity 0.71-0.98; PPV 0.11-0.33 & NPV 0.97-1.00.	Low PPV suggests TQS should be used alongside other assessments.

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Mung'ala-Odera V et al (2006).,	Kenya	LIC	Community settings in poor rural area of Kenya	Phase one 10,218 age 6-9 years. Phase two 810 screen positives, 766 screen negatives	Prevalence study on neurological disability and impairment (NI)	Ten Questions Screen administered by field workers and evaluation by clinician and psychologist for phase two	The prevalence for moderate/severe NI was 61/1000. The most common domains affected were epilepsy (41/1000), cognition (31/1000), and hearing (14/1000). Motor (5/1000) and vision (2/1000) impairments were less common. Of the neurologically impaired children (n 5 251), 56 (22%) had more than one impairment. Neonatal insults were found to have a significant association with moderate/severe NI in both the univariate (OR 1.70) and multivariate analyses (OR 1.30)	CBR services need to be instituted to support people with disabilities arising from NI

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Nair MK, Radhakrishnan SR (2004).	India	LMIC	India (Review Article)	n/a	Review article including information on tools for identifying developmental delay	Developmental Observation Card (for mothers); Trivandrum Developmental Screening Chart (TDSC for field staff such as health workers, creche workers); Child Development Centre grading for motor milestones	A World Bank project in Kerala has involved Developmental Therapists training 9258 AWWs to detect developmental delay and the TDSC is routinely used by the AWWs of Kerala to screen infants for developmental delay.	see CDC website http://www.pediatricskerala.com/html/childdvlpcentre.htm#o2

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Nair MK et al (1991).	India	LMIC	Hospital clinic and community based sample in Kerala, India	Total 1945 children age 0-2 years (455 community sample; 1500 well child clinic sample); 141 cross validation with Denver Developmental Screening Test	Development and validation of a simple screening tool for health workers	Trivandrum Developmental Screening Chart (TDSC). 17 items e.g. social smile, says two words. A vertical line is drawn, or a pencil kept vertically, at the level of the chronological age of the child being tested. If the child fails to achieve any item on the left side of the line they are considered to have developmental delay.	The TDSC can be done in 5 minutes by a health worker. The TDSC showed clinically acceptable sensitivity of 66.7% and specificity of 78.8% against DDST as gold standard.	They note that there is no harm is missing out borderline cases of developmental delay as large scale community intervention programs are still not available. Thus they prefer high specificity. The screening chart was being field tested for use by AWWs in a major community study.

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Nair MK et al (2009).	India	LMIC	Anganwadis	100 toddlers for validation study. 429 toddlers for standardization study	Development, validation, standardization	Developmental Assessment Tool for Anganwadis (DATA). Milestones selected from existing developmental measures e.g. Denver DST, Developmental Assessment Scale for Indian Infants (DASII).	12-item DATA developed. Internal consistency, face validity, content validity and construct validity found to be appropriate. DATA score between 33 and 28 suggested 'at risk' for developing developmental delays. A score of ≤27 suggested already delayed milestones. A score of 27 to 16 suggested a 'mild delay', a score of 15 to 5 suggested a 'moderate delay' and ≤4 suggested a 'severe delay' in development.	DATA was administered by experienced developmental therapists. Field trials with administration by AWWs are needed. Subgroup analysis (e.g. Gender) in relation to standardization not done.

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Phatak AT, Khurana B (1991).	India	LMIC	Community settings	n/a	Scale description	Baroda Development Screening Test for infants up to 30 months. 54 items selected from the Bayley Scales of Infant Development which has been standardized on 4141 normal Baroda babies (Baroda norms)	The screening test was put to use in the field survey as well as in clinical practice (especially well baby clinics). It had been used for more than 3 years by CHWs of Baroda. 5 or 6 one hour sessions are sufficient for training on screening. Information on sensitivity and specificity is reported to by 65%-95% in this paper but this is based on a personal communication.	Although the BSID (Baroda Norms) is regularly used at 6-7 research centres in India, the DDST appears to be the better known amongst paediatricians. Conclude that the Baroda Development Screening Test could have a wide application in field surveys and clinical practice.

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Pongprapai S et al (1996).	Thailand	LMIC	Rural communities in deprived district in Southern Thailand	4366 children under 15 years of age screened; 185 who screened positive assessed	Prevalence & validity of screen	Phase One TQS; second phase evaluation by medical students; third phase evaluation by rehabilitation physician	In stage one, 185 screened positive; in stage two 68 confirmed to have impairments; in stage 3 53 confirmed to have impairments. Overall prevalence of disability 1.21% of whom 7.9% had ID. Many false positives at stage one was due to isolated instances of febrile convulsions pointing to need to alter the question on fits.	Almost half of the children had received virtually no assessment and care from Western medical services. This was due to both the inaccessibility and cost of such services and to traditional beliefs and practices of their culture. Two thirds of the children would be expected to receive a definitive and practical advantage from modern rehabilitation and/or surgical service.

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Scherzer A (in press).	Cambodia	LIC	Regular out-patient clinic at children's hospital	300 (100 in 2007; 200 in 2008) age range 6 weeks to 7 years	Clinical trials of feasibility of using DMC during regular clinic visits	Developmental Milestone Chart (DMC) - single page check off chart designed for this outpatient clinic (included as appendix). Milestones selected and modified from existing literature e.g. Denver DST, Denver II.	In 2007 25% and 2008 32% failed to achieve one or more age-appropriate milestones. Fine motor activities such as copying a circle, square or triangle appeared to be more challenging for some otherwise age appropriate children in the clinic setting.	Further work is needed to refine the DMC in terms of cultural relevance and to evaluate the number of milestone failures that should be used to reflect delay in order to avoid excessive false positives. There is no information on DMC specificity, sensitivity, test-retest and inter-rater reliability, or predictability.

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Singhi P et al (2007).	India	LMIC	House to house interview survey in three villages in rural area of North India	Pilot study with 60 children. Screening study 1763 age 2-9 years	Validation and utility assessment of screening tool	First stage TQS and second phase clinical evaluation	A total of 1763 children were screened from 3 villages with a total population of 5830. 5.1% of boys and 3.4% of girls screened positive. The sensitivity and negative predictive value were found to be 100%. The positive predictive value of the screen for significant disabilities was 50%. Positive predictive value higher for boys (61%) than for girls (31%). Only 8% of parents/guardians were aware of rehabilitation programmes for disabled children being run in their area.	Some of those classed as "false positives" would have benefited from referral as 23% of the false positives had mild delay due to malnutrition. TQS is a low-cost-quick screening tool that can be used by community workers but not as an assessment tool. Further questions about autism or ADHD could increase the scope and completeness of the screen.

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Soleimani F, Dadkhah A (2008).	Iran	LMIC	Infants referred to health network for routine care and vaccination	6150 aged 4-18 months	Validation	Infant Neurological International Battery (INFANIB). INFANIB has 20 items to assess the infant age 4-18 months for gross motor developmental delay	Mean time for scoring the INFANIB test was 8-10 mins. The INFANIB was valid for the normal and abnormal group with 90% sensitivity, 83% specificity, 79% PPV and 93% NPV. Also the reliability coefficient between the examiners (paediatrician and occupational therapists) was calculated, and the intraclass correlation coefficient was 0.90.	INFANIB only looks at motor developmental delay. Could be used in developing countries but only where there are adequate numbers of trained staff and availability of specialist neuro-developmental services.
Thorburn MJ et al (1991).	Jamaica	UMIC	Community setting in Jamaica	130 key informants; 5475 children aged 2-9 years screened	Comparison of identification methods	Key informant versus TQS screen	Key informant method found to be unsatisfactory for identifying disabilities	

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Thorburn MJ et al (1992).	Jamaica	UMIC	Community settings	Phase one 5,461 age 2-9 years; phase two 1,219	Validation	Ten Questions Screen	as reported in Durkin et al 1994	To overcome the unethical situation of identifying children without follow-up the survey was conducted in an area where a CBR programme was being established
Tombokan-Runtukahu J, Nitko AJ (1992).	Indonesia	LMIC	Children with ID and non-ID children in schools	43 ID matched with 43 non-ID children aged 6-18 years	Adaptation of a Western measure of adaptive behaviour to the Indonesian context and analysis of psychometric properties	Through translation and adaptation of the Vineland Adaptive Behaviour Scales (VABS) Survey Form the Indonesian VABS (IVABS) was formed consisting of 245 items.	Psychometric characteristics were similar to that of the American version of VABS.	The research does not warrant immediate implementation of IVABS on a national basis due to limitations of this study and the need for further validation and standardization

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
van Meerbeke AV et al (2007).	Colombia	LMIC	Convenience samples from schools and daycare centres in Bogota, Colombia. Most below poverty baseline.	2,043 preschool children (<5 years). 287 subject to neuro-development evaluation	Prevalence study	Carers completed questionnaire about possible neurological disorders in their families and teachers asked for list of children with suspected disorder. Those who were "suspect" evaluated using The Abbreviated Developmental Scale 1 (EAD-1) battery designed and validated in Colombia. Used as the primary tool for the evaluation of development in Colombian children.	Of 2,043 children, 287 evaluated using EAD-1. One or more abnormal items (alert category) were found in 67 (23.3%) children, for an estimated prevalence of 32.8 per thousand children <5 years of age, including deficits in gross motor function (9.3 per thousand), personal-social interactions (9.8 per thousand), fine motor skills (10.3 per thousand), auditory language delay (18.6 per thousand) and overall delay (10.8 per thousand).	Identified NDD among apparently healthy children from nurseries and kindergartens, who had previously been undiagnosed and untreated. Lack of evaluation of developmental milestones in children in Colombia is a substantial public health problem that will require effective intervention.

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Vazir S et al (1994).	India	LMIC	Community settings from 3 regions of India	13,000 children under 6 years of age	Development & standardization	The Indian Council of Medical Research (ICMR) Developmental Screening Scale for Indian Rural Children. 66 milestone items which form a simple, culturally appropriate screen for psychosocial development for administration by CHWs.	7 centile levels for each of the 66 milestones are presented and age of attainment at 50th centile used for age placement of that item. Inter-tester reliability ranged from 95-98% and retest coefficients from 95-99%.	CHWs were trained to assess age using a local event calendar for children without birth certificates. It is proposed that the scale could be used to detect children at the community level for developmental delay.

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Wirz S et al (2005).	Sri Lanka and Uganda	LMIC & LIC	Community health worker run clinics in Sri Lanka and Uganda	23 community health workers; 769 children Uganda; 580 children Sri Lanka	Field testing of ACCESS Portfolio for identifying children with disabilities and offering advice. Health workers trained, children screened, 10% of screened children assessed by experts.	ACCESS Portfolio which has an identification section and an advice section. Includes 'Messages for mother'; WHO Growth Charts (local versions); TQS; Jamaican adaptation of the Denver Developmental Screening Test; WHO play materials; short screen about vision; short screen about hearing and communication	769 children were screened in Uganda and 580 in Sri Lanka. In Uganda, 44% of children seen failed the screen and in Sri Lanka 11% failed and were deemed to have a disability by the health workers. Developmental delay and difficulties with movement and self-care were the commonest cause of disability identified. Field workers identified disabilities in children over age 2 with 82% accuracy compared with professionals.	Both health workers and parents found the process clear and useful. Parents found the advice materials helpful. Some health workers thought the manual was too bulky. They felt there were some omissions e.g. epilepsy not covered well, and training in counselling for family members needed.

Study	Country	World Bank Classification	Setting	Sample Size	Design or purpose	Instrument	Results	Other Comments
Zaman SS et al (1990).	Bangladesh	LIC	Community settings ranging from Urban slums to affluent areas in Dhaka	Phase one: 2576 age 2-9 years; phase two 359.	Validation with focus on gender and age	TQS	Overall more boys screened positive (7.7%) than girls (5.8%) but ns. No major age or gender differences in the validity of the questionnaire were apparent. Sensitivity, specificity and negative predictive value were perfect or near perfect for severe or moderate disabilities. PPV for serious disabilities was only 22%	70% of false positives had mild disabilities or other conditions for which early detection and treatment could be beneficial. Despite the number of false positives it reduces the number of children to be evaluated by professionals from 100% to just the around 7% who screen positive on the TQS.

Summary analyses

Summary characteristics of screening tests:

Instrument	Study	Country	Sample Size	Design[1]	Sensitivity	Specificity	PPV	NPV	Other Validity	Reliability[2]
Abbreviated Developmental Scale (EAD-1)	Van Meerbeke AV et al (2007).	Colombia	2,043 children aged <60 months	CS	NK[3]	NK	NK	NK	NK	NK
ACCESS Portfolio	Wirz S et al (2005)	Sri Lanka and Uganda	769 children Uganda; 580 children Sri Lanka	CS/Field test	NK	NK	NK	NK	Accuracy 76-82%	NK
Baroda Development Screening Test	Phatak AT, Khurana B (1991).	India	n/a	Scale description	65%-95%[4]	65%-95%	NK	NK	NK	NK
Developmental Assessment Tool for Anganwadis (DATA)	Nair MK et al (2009).	India	100 toddlers for validation study. 429 toddlers for standardization study	CS	NK	NK	NK	NK	Face and content validity reported to be high. Factor analysis yielded 2-factor model explaining 56% of variance.	IC 0.86

[1] CS = cross sectional
[2] IC = internal consistency measured using Chronbach's alpha
[3] NK = not known
[4] Sensitivity & specificity is reported to by 65-95% in this paper but this is based on a personal communication

Instrument	Study	Country	Sample Size	Design[1]	Sensitivity	Specificity	PPV	NPV	Other Validity	Reliability[2]
Developmental Milestone Chart (DMC)	Scherzer AJ (in press).	Cambodia	300 (100 in 2007; 200 in 2008) age range 6 weeks to 7 years	Clinical trials	NK	NK	NK	NK	NK	NK
Developmental Observation Chart	Cited in Nair MK, Radhakrishnan SR (2004).	India	NK	NK	NK	NK	NK	NK	NK	NK
Developmental Screening Inventory (DSI)	Aina OF, Morankinyo O (2001).	Nigeria	128 children aged 2-30 months	CS	NK	NK	NK	NK	Concurrent validity against BSID - correlations significant at p<.01	IC 0.64
Disability Screening Schedule (DSS)	Chopra G et al (1999).	India	3560 children aged 0-6 years; 2nd phase 219 'impaired' & 536 'normal' children	CS	0.89	0.98	NK	NK	NK	NK
Guide for Monitoring Child Development (GMCD)	Ertem IO et al (2008).	Turkey	510 aged 0-24 months. 2nd phase 184 medical students/92 children	CS	0.88	0.93	0.84	0.94	Concurrent validity against comprehensive paediatric assessment showed overall agreement of 91.1%	IC 0.95; interrater reliability kappa scores 0.83-0.88

Instrument	Study	Country	Sample Size	Design[1]	Sensitivity	Specificity	PPV	NPV	Other Validity	Reliability[2]
Indonesian Adaptation of the Vineland Adaptive Behavior Scales (IVABS)	Tombokan-Runtukahu J, Nitko AJ (1992).	Indonesia	43 ID matched with 43 non-ID children aged 6-18 years	CS	NK	NK	NK	NK	Psychometric properties of IVABS found to be similar to American VABS	Interrater reliability R .80 to .98. Test-retest reliability .86 to .99
Infant Neurological International Battery (INFANIB)	Soleimani F, Dadkhah A (2006).	Iran	6150 aged 4-18 months	CS	0.9	0.83	0.79	0.93	NK	Interrater reliability R=0.9
Malawian Developmental Screening Tool	Gladstone M et al (2008).	Malawi	1st stage piloting 20; 2nd stage piloting 20; standardization 1130 children age 0-6.5 years	CS	NK	NK	NK	NK	Considered to have good face and content validity based on expert assessment	Interrater reliability kappa >0.4 for 82% of items. Intrarater figure 75% of items with kappa >0.4.

Instrument	Study	Country	Sample Size	Design[1]	Sensitivity	Specificity	PPV	NPV	Other Validity	Reliability[2]
Monitoring Child Development at Family & Community Level	Lansdown RG et al (1996).	China, India & Thailand	28,139 children age 0-6 years	CS	NK	NK	NK	NK	NK	Interrater reliability/intrarater reliability: China 0.95/0.91; India 0.90/0.95; Thailand 0.96/0.92.
National Institute for the Mentally Handicapped Developmental Screening Schedule (NIMH-DSS)	Arya S (1991).	India	Piloting 180 aged 0-6 years; validation 600 age 0-6 years	CS	0.79	0.99	100%	95%	False negatives 0.8%; false positives 1%	NK
Parents Evaluation of Developmental Status (PEDS)	Malhi P, Singhi P (2002).	India	79 parent-child dyads (child age 24-60 months)	CS	61.50%	65.20%	25.80%	89.60%	NK	NK
Psychosocial Developmental Screening Test	Vazir S et al (1994).	India	13,000 children under 6 years of age	CS	NK	NK	NK	NK	NK	Interrater reliability 95-98%. Test-retest reliability 95-99%

Instrument	Study	Country	Sample Size	Design[1]	Sensitivity	Specificity	PPV	NPV	Other Validity	Reliability[2]
Ten Questions Screen	Durkin MS et al (1994); Durkin MS et al (1995); Zaman SS et al (1990).	Bangladesh (B), Jamaica (J), Pakistan (P)	Phase one 22,125 age 2-9 years; phase two 3,983	CS	B 0.87 J 0.56 P 0.85[5]	B 0.93 J 0.85 P 0.88	B 0.09 J 0.07 P 0.18	B 1.00 J 0.99 P 0.99	Factor loadings consistent over 3 populations	IC 0.60-0.66 Test-retest reliability kappa 0.58-0.83
Ten Questions Screen	Mung'ala-Odeva V et al (2004).	Kenya	Phase one 10,218 aged 6-9 years; phase two 810 screen positives & 766 screen negatives	CS	0.70-1.00	0.71-0.98	0.11-0.33	0.97-1.00	NK	Test-retest kappa values 0.2-1.00
Ten Questions Screen	Singhi P et al (2007).	India	Pilot study with 60 children. Screening study 1763 age 2-9 years	CS	1.00	0.74	0.50	1.00	NK	NK

[5] These figures are for serious cognitive, motor and/or seizure disability. Vision and hearing omitted due to low sensitivity

Instrument	Study	Country	Sample Size	Design[1]	Sensitivity	Specificity	PPV	NPV	Other Validity	Reliability[2]
Trivandrum Developmental Screening Chart (TDSC)	Nair MK et al (1991).	India	1945 children age 0-2 years (455 community sample; 1500 well child clinic sample); phase 2 141	CS	66.70%	78.80%	NK	NK	NK	NK

Directness (in terms of population, outcome, intervention and comparator)

The review was concerned with the use of identification and screening tools for children with intellectual disabilities in low and middle income countries. There was no indirectness for the population and intervention. Studies reporting on the field testing of screening tools for day to day use, as opposed to studies focussing on validation or prevalence, are rare, the notable exception being a field test of the ACCESS portfolio (Wirz et al, 2005). Therefore, outcome may not be so direct.

Any additional information (safety and tolerability issues, cost, resource use, other feasibility issues, as appropriate)

Further points with regard to developmental testing in LAMI countries have been noted (Ertem et al, 2008): caregiver literacy limits the use of written questionnaires and checklists; if developmental difficulties are prevalent in the population caregivers may not know how children should develop, meaning one cannot rely on caregivers identifying concerns as a screening method by itself; if asking about milestones, caregivers may be reluctant to say their child has not achieved the milestone as they may not believe that interventions exist or worry about the stigma related to developmental delay; and reliance on "child testing" methods is neither practical nor desirable. Ertem et al (2008) conclude that: "Family centered methods for monitoring child development that have evolved in the West should be the methods of choice for developing countries as well" p582. Further they suggest that monitoring child

development is a new concept in LAMIs and methods should be built on existing protocols such as growth monitoring and immunisations (Ertem et al, 2008).

Narrative conclusion

This review has identified a number of screening tests that have been constructed for use in LAMI countries to identify disabilities in children. The major focus of work in LAMI countries has been the identification of generic disabilities through the administration of short screening tools by community based "grass roots" workers, such as community health workers (CHWs) and anganwadi workers (AWWs), or other grass roots workers depending on the cultural context. There is little research regarding the identification of disabilities by health professionals such as doctors or nurses in clinical settings, the notable exceptions being conducted in Cambodia (Scherzer, *in press*) and Iran (Soleimani & Dadkhah 2006). The focus on generic disabilities means that the identification of ID is mostly done within the context of identifying a range of childhood disabilities.

A number of criteria have been outlined for appropriate screening tools for LAMI countries. They must be: quick; low cost; acceptable to the community; easy to use by grass root level workers; and have high specificity and sensitivity as false positives are costly in terms of professional time and anxiety to families, and false negatives may impact on the child's health (Chopra et al, 1999).

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From evidence to recommendations

Factor	Explanation
Narrative summary of the evidence base	38 articles were identified that looked at identification of children and adolescents with intellectual disabilities in low and middle income countries. Most studies are primarily concerned with identifying child disability per se. However, it is possible to conclude from this body of research that two general approaches to the development of screening measures hold promise. 1. Valid and relatively efficient screening measures based on the reported attainment of culturally-appropriate age-specific developmental milestones have been developed for use in a number of LAMI countries. 2. The Ten Questions Screen (primarily based on reported concerns about the child's relative development) has been shown to have acceptable levels of validity and efficiency in the identification of general child disability in LAMICS.
Summary of the quality of evidence	Evidence relating to the validity of *specific* approaches to identifying *intellectual disability* in children in LAMI countries is of low quality. There is no indirectness in terms of population or setting.
Balance of benefits versus harms	Variation in caregiver knowledge of 'normal' development and the spatial clustering of disability may reduce the effectiveness of approaches based on reported concerns about child *relative* development. False positives are costly in terms of professional time and anxiety to families, and false negatives may impact on the child's health (Chopra et al, 1999).
Values and preferences including any variability and human rights issues.	There are, however, difficulties associated with both approaches related to the stigma associated with disability or developmental delay. Attitudes to ID in LAMI countries may also have an influence on the accuracy of testing.

	Parents or guardians may be reluctant to say their child has a disability in a culture where such disabilities may be highly stigmatizing. Further, in some countries it has been suggested that there may be a tendency to over-report problems in boys and under-report problems in girls due to a cultural preference for boys which leads to parents displaying more concern for the health of sons than daughters (Singhi et al, 2007; Zaman et al, 1990). Further, it has been noted that there can be no single universal test of psychosocial skills and individual countries should be encouraged to devise their own culturally appropriate scales with their own normative data (Lansdown et al, 1996). Identification should be completed with management and interventions. Especially identification and management of some conditions in early infancy can prevent further aggravation of the disability. This is an important "right to health" principle that should not be overlooked.
Costs and resource use and any other relevant feasibility issues.	Use of Western instruments in non-western settings is not always feasible or appropriate. Assessment in developed countries often uses Western developmental tools (e.g. Bayley scales, Griffiths, McCarthy scale, and the Denver II) which have been designed and validated in Western countries (Gladstone et al, 2008). These may be tailored for use in non-Western settings and often translation into another language is all that is done. However, translation alone may not allow for local expressions and customs, leading to the misinterpretation of results (Gladstone et al, 2008). Tools such as "The Ten Questions Screen" are more appropriate for use in low LAMICs.
Recommendation(s) Non-specialized health care providers should consider further assessment of children suspected of intellectual and other developmental delays by brief, locally-validated questionnaires. Strength of recommendation: STANDARD Non-specialized health care providers should consider clinical assessment to identify common causes of these conditions under supervision of specialists, if available and may offer management or referral as appropriate. Strength of recommendation: STANDARD	

Non-specialized health care providers should consider monitoring children's intellectual, social and emotional development routinely as part of the mother and child health programmes using locally-validated tools.
Strength of recommendation: STANDARD

Update of the literature search – June 2012

In June 2012 the literature search for this scoping question was updated. The following systematic review was found to be relevant without changing the recommendation:

Robertson J, Hatton C, Emerson E, Yasamy MT. The identification of children with, or at significant risk of, intellectual disabilities in low- and middle-income countries: a review. J Appl Res Intellect Disabil. 2012 Mar;25(2):99-118. doi: 10.1111/j.1468-3148.2011.00638.x