Screening for developmental delay- should we and if so how?

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250 million children with developmental delay

93 million with a disability

90% of these in LMIC settings

Likely number of children more likely to be approx 290 million – awaiting updated GBD
Screening or Surveillance

- **Screening**: looking for the presence of a disease or other unwanted condition using a test.

- **Surveillance**: looking actively for something that has gone wrong, or is about to go wrong, using continuous clinical information.

1. The condition sought should be an important health problem.
2. There should be an accepted treatment for patients with recognized disease.
3. Facilities for diagnosis and treatment should be available.
4. There should be a recognizable latent or early symptomatic stage.
5. There should be a suitable test or examination.
6. The test should be acceptable to the population.
7. The natural history of the condition, including development from latent to declared disease, should be adequately understood.
8. There should be an agreed policy on whom to treat as patients.
9. The cost of case-finding (including diagnosis and treatment of patients diagnosed) should be economically balanced in relation to possible expenditure on medical care as a whole.
10. Case-finding should be a continuing process and not a “once and for all” project.

Wilson and Jungner 1968
Screening or surveillance?

- Screening
- Surveillance
- Prevention of risk factors
- Support
- Treatment
Screening for developmental delay using developmental tools? What are the issues?

- Focuses on child, does not cover bioecological theory.
- Cross-sectional, whereas development is longitudinal.
- No consideration for pre-screen prevention.
- Gives score or delayed/not delayed; does not show where child is, nor how to help child achieve potential.
- Not necessarily building partnerships with family or lead to supporting development and early intervention.

- Ertem IO. Developmental Difficulties In Early Childhood, WHO Publications 2012
Is developmental screening the same as screening for childhood disability?

**Developmental assessment** is a measure of functioning BUT NOT ALWAYS IN ALL AREAS

- Spiritual & Moral
- Language
- Cognitive
- Social & Emotional
- Self-Help & Adaptive
- Gross Motor
- Fine Motor

Does not assess STRUCTURE e.g. the way the child looks or ENVIRONMENT (Risk factors)

**Screening for disability** may be to identify impairments in VISION, HEARING, MOTOR TONE, BEHAVIOUR, QUALITY OF MOVEMENT, FEEDING etc

Need to assess across the ICF however!
Developmental milestones vs. Red flags

• Developmental milestones and variation with age

• Red flags may be YES or NO at any age

• E.g. CP – “Does the child’s tone feel equal on both sides of the body?”

• E.g. ASD – “Does your child point to show you something that is out of reach AND turn to look at you?”

• E.g. ADHD – Does your child have poor concentration or impulsive behaviour?
So how can we screen for disability particularly when resources are limited?
Ten Question Screen

Compared with other children:
1. Delay in sitting, standing, or walking?
2. Difficulty seeing
3. Difficulty hearing
4. Difficulty understanding
5. Difficulty walking or moving

Does the child:
6. Experience fits
7. Learn
8. Speak at all
9. Speech different (3-9)
9. Name at least 1 object (2)
10. Appear “Mentally backward, dull or slow”?
International classification of functioning, disability and health (ICF)

• An individual’s functioning is an interaction between health, environment and personal factors.
How to measure disability

Measurement options

2. Self Reported Functional Limitations

Do you have difficulty

1. Seeing
2. Hearing
3. Walking/Climbing
4. Remembering/concentrating
5. Self Care
6. Understanding/being understood?

Response Options:
(1) No difficulty
(2) Yes, some difficulty
(3) Yes, a lot of difficulty
(4) Cannot do at all
How to measure disability

Will this capture main types of disability?

Do you have difficulty

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Response Options:
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UNICEF-Washington Group Child Set

Difficulties with:

- Seeing
- Hearing
- Walking
- Self-care
- Being understood
- Learning
- Remembering

- Concentrating
- Accepting changes
- Controlling behaviour
- Making friends
- Anxious, nervous, worried
- Depressed
Key informant methods (KIM):

- Knowledgeable members of the COMMUNITY IDENTIFY children with disabilities
- Children then screened by medical professionals - referred on for health or educational interventions.
- Less costly and time consuming than surveys
- As effective as the TQQ – high rates of case detection but LOW specificity.
- Direct connection to appropriate referral services (pre-emptive mapping) collating information on service availability and affordability.
- Can engage local communities and stakeholders and proposes to build capacity and knowledge sharing and encourage strategy planning that is locally feasible, needed and relevant.
Yes – services can be mapped (E.g. From Bogra)

Developing networks for services through identification (KIM)

Slide from H Kuper at:

LONDON SCHOOL OF HYGIENE & TROPICAL MEDICINE
Apps and devices for screening hearing and vision? Not yet for <2 years at low cost.
So, are there any globally available tools that can help?
RNDA – Rapid Neurodevelopmental Assessment of Children
GMCD - Child Monitoring (0-5 years)

- GMCD – good for settings where resources are enough for training and support of those who can do “assessment and diagnosis”.

- Three goals: prevention, early identification, early intervention
- Three theoretical constructs: Bioecological, family-centered, ICF
- Three components
- International construction
The MDAT – Malawi Developmental Assessment Tool
Global goods? Websites, downloadable materials, training on tools that show good validity and reliability.

- GM1: Lifts chin off floor

  ❖ Put the child on his/her stomach on a flat surface. See if the child can at least lift his/her head so that the chin is off the surface for a short period of time.
Can any of these be put into present systems of care?
Screening within a health system - RBSK

Materials required for screening

Head Circumference Tape

Mid Arm Circumference Tape

RED RING

- Ring tied to a thread & dangled in front of the baby
- Visual fixation and tracking
- Reaching for objects ≥ 4 months

RATTLE

- To attract infant’s attention
- To test response to sound in young infants (Observe Behavioral responses)
- Holds rattle when placed in hand (≥ 12 weeks)

Refer to job aid for instructions and pictures

A. Deformities at Birth

If Yes, refer

A1. Head - Abnormally large or small; skull shape deformity, Sprengel’s folds, microcephaly

A2. Eyes - Any visible abnormality (e.g. pouting, Squint) Important sign after 1 month, frequent eye movements, inability to follow an object

A3. Ear - Any abnormality of shape

A4. Lips and Palate - Cleft (complete or incomplete)

A5. Difficulty in sucking and swallowing


A7. Nuchal Defect

A8. Limbs - Any deformity or club foot

A9. Spine - Neurocutaneous defects

A10. Lower Limb Suggestion of Down Syndrome (Fetoscopy) *(Refer if there are any signs of concern)*

A10(a). Eye: apparent downward or inward turn of eye, corneal edema, enlarged corneal reflector, globe misshapen, nystagmus, strabismus

A10(b). Neck: Cervical lordosis/kyphosis

A10(c). Ear: flattened, misshapen, malformed

A10(d). Hand: Short stature, microcephaly, special dermatoglyphics

A10(e). Feet: Wide gap (diastema) between the great toe and second toe

A11. Congenital Heart Disease

A12. Bilateral Microtia and Abnormal Ear Canal or Ossicles in Ushaped fold or Fumey's Syndrome change in hairline or Hu syndrome

B. Deficiency

If Yes, refer

B1. Sickle cell Haemoglobin (HbSS) - Red cells less than 5%, normal HbA+HbC less than 10%, abnormal Hb's

B2. Sickle cell Trait (HbAS) - Sickle cell trait

B3. Severe anaemia - Look for severe paleness pallor

B4. Vitamin A Deficiency - Ask for right blind spot (foveal) patchy patches on sclera

B5. Vitamin D Deficiency - Ask for breast induration/fixation of local tenderness involving the chest
Surveillance within the health system
How can we link screening or surveillance with action for children?
Trans-diagnostic approaches (Mental health)

Model for Service Delivery for Developmental Disorders in Low-Income Countries

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FIGURE 2
Tablet-based ACT system.
The Six F-Words for Childhood Disability

1. Function
   - I might do things differently but I can do them when I do it is important. Please let me try!

2. Family
   - They know me best and I trust them to do what’s best for me. Listen to them, talk to them, hear them, respect them.

3. Fitness
   - Everyone needs to stay fit and healthy including me. Help me find ways to stay fit.

4. Friends
   - Having childhood friends is important. Please give me opportunities to make friends with my peers.

5. Fun
   - Childhood is about fun and play. This is where I learn and grow. Please help me do the activities that I find the most fun.

6. Future
   - I will grow up one day to please find ways for me to develop independence and be included in my community.


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