Developmental screening: Pitfalls and pathways

Professor Frank Oberklaid
Centre for Community Child Health
Royal Children’s Hospital Melbourne

‘Big Idea’ at 2020 Summit

• ‘My big idea is to institute a check for all children at 2 years of age. In this way we could pick up problems before they occur, or in the very early stages, and then offer treatment at that point in time. This would be a very effective way of improving children’s outcomes …’

- Senior government minister

Outline of presentation

• Review of the science of early detection
• Apply these principles to developmental screening
• Suggest that the concept of ‘developmental screening’ does not represent good science, and never will
• Outline a broader framework for the early detection of problems in young children

Definition of screening

‘Screening is the presumptive identification of unrecognised disease or defect by application of tests, examinations or procedures which can be applied rapidly. Screening sorts out apparently well persons who probably have a disease from those who probably do not. A screening test is not intended to be diagnostic.’

- US Commission on Chronic Illness, 1957

Screening program

‘In a screening program, a test or series of tests is performed on a population that has neither the signs nor symptoms of the disease being sought but whose members have some characteristics that identifies them as being at risk from that disease, the outcome of which can be improved by early detection and treatment. Screening actually consists of all steps in a program from the identification of the population at risk to the diagnosis of the disease…to the treatment of those individuals.’

- Muir Gray, 1997

Terms used in appraisal of screening test

• Sensitivity - proportion of people with condition who are correctly identified
• Specificity - proportion of people who do not have the condition who are correctly identified be a negative test result
• False positive - person incorrectly identified by a positive test result who does not actually have the condition
• False negative - person incorrectly identified by a negative test result who does actually have the condition
Terms used in appraisal of a screening program

- **Efficacy** - the outcome under **ideal** conditions
- **Effectiveness** - the outcome under **normal, everyday** conditions

A test or an intervention may have good efficacy but poor effectiveness.

---

Characteristics of a screening test

*(Cochrane & Holland, 1971)*

- Simple, quick and easy to interpret; capable of being performed by paramedics
- Acceptable to the public, since participation is voluntary
- Accurate
- Repeatable
- Sensitive
- Specific

---

Criteria for a screening program

*(Wilson & Jungner, 1968)*

- Condition should be an important health problem
- Accepted treatment for patients with the disease
- Facilities for diagnosis and treatment available
- Recognisable latent or early symptomatic stage
- Suitable test or examination
- Acceptable to the population
- Natural history understood
- Agreed policy on whom to treat

---

Characteristics of a Screening Test

| PKU | Simple, quick and easy to interpret | ✓ |
|     | Acceptable to the public | ✓ |
|     | Accurate | ✓ |
|     | Repeatable | ✓ |
|     | Sensitive | ✓ |
|     | Specific | ✓ |

---

Characteristics of a Screening Test

| Language | Simple, quick and easy to interpret | ✗ |
|          | Acceptable to the public | ✗ |
|          | Accurate | ✗ |
|          | Repeatable | ✗ |
|          | Sensitive | ✗ |
|          | Specific | ✗ |
Criteria for a Screening Program

Language

<table>
<thead>
<tr>
<th>Important health problem</th>
<th>✓</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accepted treatment</td>
<td>✓</td>
</tr>
<tr>
<td>Facilities for diagnosis and treatment</td>
<td>?</td>
</tr>
<tr>
<td>Latent or early symptomatic stage</td>
<td>?</td>
</tr>
<tr>
<td>Suitable test or examination</td>
<td>?</td>
</tr>
<tr>
<td>Test acceptable to the population</td>
<td>✓</td>
</tr>
<tr>
<td>Natural history adequately understood</td>
<td>✓</td>
</tr>
<tr>
<td>Agreed policy on whom to treat</td>
<td>✓</td>
</tr>
<tr>
<td>The cost of case-finding balanced with expenditure on medical care as a whole</td>
<td>?</td>
</tr>
</tbody>
</table>

Characteristics of a Screening Test

Development

| Simple, quick and easy to interpret | ✓ |
| Acceptable to the public | ✓ |
| Accurate | ? |
| Repeatable | ✓ |
| Specific | ? |

Properties of developmental screening tests

- Ages and Stages (0-60 months)
  - Sensitivity 70-90%
  - Specificity 76-91%
- Brigance screens (21-90 months)
  - Sensitivity 75%
  - Specificity 60%
- Child Development Inventories (3-72 months)
  - Sensitivity >75%
  - Specificity 70%

Properties of developmental screening tests

- Denver II (0-6 years)
  - Sensitivity 43-80%
  - Specificity 56-83%
- Parents’ Evaluation of Developmental Status - PEDS (0-8 years)
  - Sensitivity 74-79%
  - Specificity 70-80%

Screening

- Scientifically valid for some conditions, mainly in the neonatal period
- Suitable for conditions where condition is ‘present’ or ‘absent’ - i.e. clear categorisation into yes or no
- Not suitable for development, language or behaviour
Screening for development, language, behaviour

- Multidimensional across numerous axis
- Complex biological/environmental pathways
- Exist on a continuum; categorisation into pass/fail artificial - has no logical basis
- Does not meet scientific screening criteria for condition (natural history, who and how to treat etc) or for test (low sensitivity and specificity)
- Many children who would ‘pass’ screening test might still benefit from intervention

Surveillance

- Flexible, continuous process broader in scope than screening
- Initiated by professionals but involves partnerships with parents
- Knowledgeable professionals perform skilled observations of children throughout all encounters during child health care
- Each visit is seen as an opportunity to review child’s health, development and behaviour
- Aims to optimise the health of children through the ongoing overview of the physical, social and emotional health and development of all children

Components of surveillance

- Measurement of physical growth
- Monitoring developmental progress
- Administration of screening tests
- Prevention of disease - immunisation
- Providing information and support to parents
- Health education
- Eliciting and responding to parental concerns

Prevention

- Primary - prevent the occurrence of the disease - eg immunisation, effective health education programs
- Secondary - prevent the development of disease by early detection - eg PKU, hypothyroidism screening
- Tertiary - impede the progress of established disease or disability through effective intervention - eg SNHL, language disorders, developmental delay

Surveillance

Many advantages over screening:
- Involves parents
- Takes note of context
- Flexible, ongoing, continuous process
- Seeks not only to detect problems but to promote health
But:
- Not commonly used outside the medical profession
- Concern by some parents that surveillance perceived as checking their competence as parents

Involvement of parents

- Shown to improve accuracy of clinical estimates of child development and behaviour
- Parent concerns, when carefully elicited, have been shown to fairly accurately identify development, language, behaviour problems (but not other domains such as hearing loss)
- Parents’ Evaluation of Developmental Status (PEDS)
Parents’ Evaluation of Developmental Status - PEDS

- 10 item parent questionnaire
- Flexible in use:
  - can be used before, during or clinic visit
  - can be used in different settings by different professionals
- Efficient way to identify children who might need further assessment or whose parents might benefit from information and guidance
- Begins a conversation with parents about their child’s development

Suggested changes to terminology

- Screening - confine use of ‘screening’ to neonatal tests which meet criteria for screening test
- Surveillance - more restricted definition of ‘surveillance’ for those conditions which are not suitable for one off ‘screening’ as they develop or fluctuate over time - obesity, growth problems, hypertension, etc.

Suggested changes to terminology

- Monitoring of children’s health and development
  PLUS
- Activities (universal and or targeted) designed to prevent problems and improve or promote health:
  - Elicit and respond to parent concerns
  - Provide information about health and development
- Can be one-on-one; group; community wide

Principles

- Efforts to promote good outcomes can be scheduled and opportunistic
- Activities designed to optimise outcomes should expand beyond health sector to other sectors child care, preschool etc
- Professionals should engage parents actively in discussions about the child +/- administer PEDS

The role of the professional

- Depends on the setting
- Engage in dialogue with parents about their child’s health and development
- Elicit concerns
- Provide information and anticipatory guidance
- Further assessment
- Informed referral for further assessment

Principles

- All parents likely to benefit from information about the child’s health, development and behaviour
- Most children and families will benefit from some level of support, ranging from advice and reassurance through to intensive appropriate intervention
- Risk and protective factors are dynamic and their balance changes over time; they should be elicited and addressed in a timely and appropriate manner
Summary

'We recommend a conceptual move away from tests, checklists and categorising children into pass/fail groups towards the concept that most children and families would benefit from ongoing contact with a universal system that is responsive to their needs. Ideally parent concerns would be systematically elicited and addressed; a range of interventions offered in context...

- CCCH (2001) - Report to NHMRC

Summary (cont)

'... longitudinal follow up would take place to take account of the changing nature of development and risk and protective factors; seamless referral and follow up systems would be put into place in community networks; the whole system...underpinned by a system of quality assurance to ensure that structures and processes are consistent with contemporary knowledge.'

- CCCH (2001) - Report to NHMRC

frank.oberklaid@rch.org.au

www.rch.org.au/ccch