# National Screening Committee

# Child Health Sub-Group Report on Developmental and Behavioural problems

May 2005

# Developmental problems and behavioural problems

**The condition**

**1. The condition should be an important health problem. YES**
Developmental problems include speech and language disorders (discussed separately), movement disorders and behavioural problems. There is a wide range of conditions under this general heading. The issue of screening mainly arises with problems of lesser severity, since major disabling disorders like cerebral palsy, spina bifida, severe learning disability, etc. would present clinically without screening.

Problems of lesser severity include impaired language development such as "dysphasia", milder autistic spectrum disorders, developmental co-ordination disorder ("clumsiness"), reading and writing problems in school, attention deficit hyperactivity disorder (ADHD), behaviour problems. These latter are common and important as they affect school progress.

**2. The epidemiology and natural history of the condition, including development from latent to declared disease, should be adequately understood and there should be a detectable risk factor, or disease marker and a latent period or early symptomatic stage. VARIABLE**
These are evolving conditions with varying natural history; there is a continuous spectrum with arbitrary distinction between normal and abnormal; there is a lack of evidence in some cases about effective treatment (though in the case of ADHD there is good medium term evidence of benefit for medication supported by other measures); there is a shortage of treatment resources.

**3. All the cost-effective primary prevention interventions should have been implemented as far as practicable. YES**

Little is known about primary prevention and this is not a practical proposition at present.

**4. If the carriers of a mutation are identified as a result of screening the natural history of people with this status should be understood, including the psychological implications. N/A**

***The test***

**5. There should be a simple, safe, precise and validated screening test. NO**
There are various forms of developmental screening procedures, using tests or questionnaires. The sensitivity and specificity vary according to the target disorder. In general these tests perform better for the most severe problems. They can identify current problems (concurrent validity) but are less effective who will have future problems (predictive validity). There are no studies showing better outcomes for a group offered developmental screening compared to those not screened. The few studies available, though limited,

show no benefit. The notable exception is that ADHD can be identified better by a proactive approach and since treatment is beneficial, by extrapolation, screening could be worthwhile. There are however few UK studies on this topic at present.

**6. The distribution of test values in the target population should be known and a suitable cut-off level defined and agreed. YES & NO**
In general these screening tests are based on more formal psychometric tests and the distribution of test scores is known. The difficulty in deciding what is a case and who is most likely to benefit from treatment or intervention is a major difficulty.

**7. The test should be acceptable to the population. PROBABLY**
In general, developmental screening tests seem to be acceptable to the population though the uptake and the acceptance of any intervention that may be offered is variable.

**8. There should be an agreed policy on the further diagnostic investigation of individuals with a positive test result and on the choices available to those individuals. NO**

Not well developed

**9. If the test is for mutations the criteria used to select the subset of mutations to be covered by screening, if all possible mutations are not being tested, should be clearly set out. N/A**

***The treatment***

**10. There should be an effective treatment or intervention for patients identified through early detection, with evidence of early treatment leading to better outcomes than late treatment. VARIABLE, DEPENDING ON THE CONDITION**

This evidence is weak for health care interventions except in the case of ADHD where intermediate outcomes are better with intervention. In contrast, there are many studies suggesting benefits from early educational interventions.

**11. There should be agreed evidence based policies covering which individuals should be offered treatment and the appropriate treatment to be offered. NO**

The evidence is weak.

**12. Clinical management of the condition and patient outcomes should be optimised by all health care providers prior to participation in a screening programme. NO**
Not yet done.

*The screening programme*

**13. There must be evidence from high quality Randomised Controlled Trials that the screening programme is effective in reducing mortality or morbidity. NO**

With ADHD there is evidence that treatment is useful but not that population screening is effective.

**14. There should be evidence that the complete screening programme (test, diagnostic procedures, treatment/intervention) is clinically, socially and ethically acceptable to health professionals and the public. LITTLE EVIDENCE, BUT PROBABLY ACCEPTABLE.**
Most interventions are acceptable except that they are often time consuming and make many demands on parents. Medication for ADHD is controversial.

**15. The benefits from the screening programme should outweigh the physical and psychological harm (caused by the test, diagnostic procedures and treatment). NOT KNOWN.**

**16. The opportunity cost of the screening programme (including testing, diagnosis, treatment, administration, training and quality assurance) should be economically balanced in relation to expenditure on medical care as a whole (i.e. value for money).NOT KNOWN.**

**17. There must be a plan for managing and monitoring the screening programme and an agreed set of quality assurance standards. NO**
Few areas have these at present.

**18. Adequate staffing and facilities for testing, diagnosis, treatment and programme management should be made available prior to the commencement of the screening programme. VARIABLE**

**19. All other options for managing the condition should have been considered (e.g. improving treatment, providing other services), to ensure that no more cost effective intervention could be introduced or current interventions increased within the resources available. NOT CLEAR**
Clinical services vary widely in delivery – optimal approach not established.

**20. Evidence based information, explaining the consequences of testing, investigation and treatment, should be made available to potential participants to assist them in making an informed choice. NO**

**21. Public pressure for widening the eligibility criteria for reducing the screening interval, and for increasing the sensitivity of the testing process, should be anticipated. Decisions about these parameters should be scientifically justifiable to the public. NO**

Public demand for treatment for conditions listed here varies and differing availability of intervention is probably confusing to parents.

**22. If screening is for a mutation the programme should be acceptable to people identified as carriers and to other family members. N/A**

**Summary**

1. Screening for these complex developmental conditions does not meet the NSC criteria. This does not mean they are unimportant – they represent a substantial volume of pathology, distress and probably, by implication, educational failure with its associated adverse outcomes.
2. Health promotion programmes are needed to apply what is known about primary prevention and to inform parents about what is normal and abnormal in child development. Health visting teams carry out this function with young children, supported by nursery and playgroup leaders for toddlers, up to school entry.
3. There must be responsive child development and disability services able to assess children referred by parents, either because of their own concerns or because of those raised by friends, relatives or other professionals.