### **National Screening Committee**

## **Child Health Sub-Group Report on Speech and Language delay**

May 2005

## Delay in speech and language acquisition (DLSA): primary and secondary delay

### The condition

### 1. The condition should be an important health problem. YES

Children with delay in learning to talk worry parents. Deafness, learning difficulties and autism are three important causes (secondary delay). Some children have severe "specific" language impairment (i.e. marked unexplained delay in language development or articulation in the absence of any apparent underlying cause).

Many children with speech and language delay also have other problems – general learning problems, poor co-ordination, behaviour difficulties, attention deficits, variable hearing loss, etc. Although the speech and language literature is remarkably silent on these other dimensions of children's developmental problems they often co-exist.

Mild and moderate primary delay are much more common. Some children understand everything said to them but have problems producing speech (expressive problems) and others also have problems in understanding speech (receptive problems).

If a cut-off on a DSLA screen were to be set at 5% of children then there would be 35,000 referrals per year. However, there are no data from which one could extrapolate to the number of adverse events occurring or avoidable.

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. NOT ENTIRELY Among otherwise normal children, there is a wide variation in the rate at which complexity of language use advances and in the developing clarity of the speech. At the slowest end of the distribution, there is a strong genetic influence on slow language development but across most of the range there are strong environmental factors. Much of the concern about DSLA is related to its association with reading difficulties and behavioural problems, both of which in turn may affect educational progress. However, the relationships are not simple.

### 3. All the cost-effective primary prevention interventions should have been implemented as far as practicable. YES, IN PART

There are several reasons to think that the number of children with DSLA could be reduced, or the distribution curve of language development moved upwards, by improving parents' understanding of the communicative needs of young children. An early intervention programme of this nature might form part of a "SureStart" approach. Similarly, early pre-reading work might enhance literacy.

There is evidence of some continuity in levels of language development between the age of 10 months and 2 years, and a group of babies can be identified who will be slower than their peers. However, the consensus is that there is insufficient evidence to apply this finding to a screening process.

It is important to assess other aspects of risk and resilience for children. Temperamental factors and relationships with adults outside the home are important. Parents' mental health is a related issue, particularly postnatal depression.

It is uncertain whether primary prevention on a community wide basis would be effective but the benefits of parent-delivered intervention in children referred with problems suggest that this merits further investigation.

# 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 many screening instruments with acceptable properties in terms of their simplicity of administration and their validity when compared to a reference test. This is not surprising as most of the screens are based on formal language tests. However the uncertainty over what counts as a "case" and the lack of evidence about who benefits are the two major obstacles to formal screening. Sensitivity and specificity are acceptable if the other issues could be resolved.

A screen for autism has been devised and evaluated. The concepts underlying it are useful for professional training but the design of the screen relies on developmental principles and it must be administered at the age of 18 months – it is not easily adjusted for different ages. This presents considerable practical difficulties as this is not an age favoured for routine contact and, even if it were, it would not be possible to reliably carry out the screen at exactly that age. The sensitivity is low when screening for autism but the specificity is high.

### 6. The distribution of test values in the target population should be known and a suitable cut-off level defined and agreed. NO

There is a continuous distribution of language skills, and no clear distinction between "a case" of DSLA and a "normal" child. Studies define divisions between normal and delayed but these are arbitrary and the choice in turn defines the prevalence. The predictive power of DSLA is low in young children except for those with severe impairments at the extremes of the distribution. 7. The test should be acceptable to the population. PROBABLY YES.

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. UNCERTAIN.

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. EVIDENCE IS MIXED After excluding the secondary cases which may need specialised intervention, a systematic review found that primary cases benefit from intervention by a speech and language therapist (SALT). Children with articulation problems do better with a SALT than with a non-professional worker but those with expressive DSLA do as well, and probably better, with SALT input delivered by a non-professional worker (parent or playgroup leader for example). The response to intervention could define a case but there are few data on the issue of whether these "case" children might have "caught up" without intervention – most studies are too short term and / or lack an untreated control group.

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

Not fully agreed either in terms of indications or in treatment plans.

#### 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

There is much variability in how referrals are handled, in waiting times and in management.

### 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

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. PROBABLY SO

Not established.

15. The benefit 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 (i.e. value for NOT care as а whole money). KNOWN The process of case-finding or screening in pre-school children is part of the assessments and visits carried out by health visitors, and costs would only become meaningful if this procedure became the main driving force for continuing a given health visiting contact. However, the costs of assessing all the children referred by health visitors and others are substantial. Furthermore the numbers involved generate long waiting lists which delay investigation and intervention for children with major problems.

# 17. There must be a plan for managing and monitoring the screening programme and an agreed set of quality assurance standards. NOT IN MOST PLACES

18. Adequate staffing and facilities for testing, diagnosis, treatment and programme management should be made available prior to the commencement of the screening programme. UNCLEAR Many areas have insufficient staff and long waiting times although the organisation of services differs widely.

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. NO More could be done on primary prevention and on other methods of identifying children with problems.

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 Not generally done in any structured way.

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. N/A

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

At the present time, a formal screening process is not appropriate for DSLA. It is nevertheless an important topic and should be kept under review. Screening is undoubtedly possible and the main difficulties lie firstly in determining the cut-off points and indications for intervention, secondly the need to take into account differing parental views, thirdly the question as to whether more should be invested in primary prevention and lastly whether a problem that is so common in socially disadvantaged areas is better treated as a public health issue with improvements in pre-school educational and social services rather than as a deficit needing intervention for individual children.

The identification of children with problems in this area is nevertheless important, for primary and particularly for secondary delays which may be due to hearing loss or other serious problems. This may be achieved by a combination of easy access services for parents with worries about their child's talking; information made available through the "Birth To Five" book (Health Promotion, England); advice from health professionals; projects like Sure Start; and, where appropriate, by a health and development review carried out by a health professional at around the age of two.

Such contacts need not be regarded as a screening test but rather as part of a general supportive approach for parents who value help with understanding their child's needs. The professional carrying out this work must be well informed about language and communicative development and should be equipped with the skills, and a properly evaluated test if they wish, to identify problems.

Speech and language therapists are well placed to judge which children may benefit from intervention and what sort of intervention should be offered. In general, there is a good prognosis for expressive (speech production) problems with adequate comprehension of speech in children under the age of 3 and watchful waiting is a reasonable approach unless the parent is very worried. Children who appear not to understand speech at the age of two upwards should be referred at once.

There should be an expert service to provide rapid evaluation of referrals so that children with real problems can be identified and investigated quickly. This implies some form of triage which by common consent needs to be performed by an experienced person, not a novice. Children with problems of comprehension must have a hearing assessment.

Screening for autism is not recommended but the lessons learned during the research programme should be made available for professional training.