MORE ON FOLLOW-UP STUDIES OF LOW-BIRTHWEIGHT INFANTS

FOLLOW-UP studies still form a sizeable proportion of the papers submitted to this journal, so it may not be out of place to consider them again here. They continue to report the later outcome for infants of increasingly low birthweight and gestational age who have been surviving in ever larger numbers since the mid-seventies. The surveys mostly still come from individual neonatal intensive-care units; and an unconscious desire must exist there to show that those long hours of effort devoted to the infants’ early care have been supremely worthwhile. And for the majority of survivors, at least, so they have been. Wide-ranging assessments using standardised tests, applied and analysed in an increasingly sophisticated manner, have shown that major impairment associated with perinatal illness has shifted downward to involve the smallest and most immature infants, previously those weighing above 1000g at birth, but now those below that weight.

However, it is often not clear whether those with disability, or even those apparently normal, are getting the help they need. Singer and colleagues (pp. 224–230 of this issue) discuss developmental sequelae in a useful study of 130 infants who had needed tracheostomy at some time during the first 13 months of life, and who had had it in place for more than one month. One-third of these children were of very low birthweight, and presumably the majority had subglottic stenosis, a lesion increasingly recognised in recent years in such infants following mechanical ventilation. The authors report that even those with the best outcome grew more slowly than normal, and had behavioural problems and speech difficulties—though surprisingly, hearing had not been systematically tested. It is acknowledged that the children needed multidisciplinary intervention to overcome their disabilities, but the inference is that they had not had it.

Similar shortcomings are reported for other disabilities. Kitchen and colleagues managed to follow prospectively all but 15 of 198 consecutively surviving very low-birthweight children to 14 years of age—a considerable achievement, though they had to admit defeat with the originally enlisted controls. 87 per cent of the children attended normal school, but half were judged to be making unsatisfactory progress there. These Australian research workers were forced to conclude that many of the children were only getting the extra help they needed irregularly, and for too brief a time. The shortage of skilled teachers (looming also in the U.K.) bodes ill for the third or so of low-birthweight children who will need sustained extra help for their learning.
difficulties if they are to reach their full potential.

Sameroff and colleagues\(^4\) have shown how the interaction of social and environmental risk factors may jeopardise a child’s intellectual competence. The families of low-birthweight children have more than their fair share of these risk factors\(^3\), and progress at school and social adjustment may be dependent on interventions to lessen their adverse impact, if and where possible. Thus service to the survivors will surely have to be built in far more to future follow-up studies—service not just to the minority with gross impairments but to the apparently normal, of whom there are now far greater numbers. Bax\(^4\) has pointed out that local paediatricians—whether hospital or community—need to be far more involved with this responsibility.

The next concern, also voiced before\(^4\), is that the parochial origin of many of the reports does not allow accurate forecasting of disability in defined populations. A form for the standard recording of central motor deficit and associated sensory and intellectual deficit was published in the last issue of the journal\(^5\). It is the final draft of a form originally devised by Evans and Alberman\(^6\), which has been discussed by research workers in Australia, the United States and Britain, and which has evolved to its present form after field trials. It is primarily designed as an epidemiological tool, to allow inter-regional and international comparison to be made of, for example, cerebral palsy. Thus the size of the problem could be determined, and the effectiveness of interventions for groups of children with the same disability assessed. The Working Party which produced this latest version has tried hard to find a solution to those problems of interpretation of clinical findings that inevitably occur when large numbers of people in various disciplines, with varying experience, examine disabled children. The Working Party recognises that interobserver variation has still not been completely overcome, but hopes that the form may now be widely used, and if necessary then further modified. Progression to unanimity of reporting these deficits would be a considerable step forward.

PAMELA A. DAVIES

References