Prevention requires identification – can we do it?

Editorial

With this number of the journal we are distributing a supplement on the prevention of neurodisability in childhood. The publication of this has been generously supported by the United Cerebral Palsy Research and Education Foundation following a workshop run by the Little Foundation. In putting these abstracts together and re-reading them after a passage of time, I found them extremely interesting. I felt cheerfully, as I wrote the introductory forward, that this would be a useful document for members of this journal even though the conclusions necessarily were somewhat gloomy in so far as prevention at the moment seems rather a way off. Nevertheless, I felt that maybe from this basis, good work could go forward both in primary and secondary prevention.

However, a small mote has arisen in my eye these couple of months since I have been doing the editorial work on the supplement, and that is the question of whether we are in a position to tell whether neurodisability has been prevented. Surely in our sophisticated and resourced – if not well resourced – communities of the developed world, we ought to be able to monitor the effectiveness of the preventive health care we provide.

But what do we have in place to monitor the variations in neurodisability? I fear the answer is precious little. This despite the fact that there are methodologies now which should allow us to monitor populations like, for example, that discussed by Willems and Evrard[1]. Child populations, because of the existence of compulsory schooling in virtually all developed countries, are accessible and could be routinely monitored – they are in some countries.

We learn more and more about genetic causes of disability and make progress with conditions such as cerebral palsy and even autism. But how to tell what's happening in the population? Risk registers are well recognized (Cans reports recent French experience, but the data is already 12 years old[2]). CP registers exist – the Western Australian one has a high profile and Hagberg's in Göteborg is the oldest. As Williams and Alberman[3] have pointed out, the quality of such registers is dependent on who fills them in and they can be inaccurate.

And there's another problem with the registers. They do not usually allow for comorbidities. Figures reporting incidence and prevalence of epilepsy, for example, are notoriously unreliable because it is unclear who is counted in.

Gillberg's group have probably some of the best data on autism but nevertheless they discovered that among children who are attending a neurological clinic for epilepsy, there are many autistic children who were not known to their autism register (and sadly too were not necessarily recognized at the neurological clinic as having autism).

Geneticists may be able to carry out whole population screens in the neonatal period if the infant has clearcut stigmata, as in spina bifida and Down syndrome. But what population does a genetic condition come from when the condition is first diagnosed at age three? Numerous follow-up studies have been done on particular populations of babies and, very specifically, low-birthweight or preterm babies. Many of these studies have the problem of population selection and the lack of control from the normal population. Many suffer an attrition rate as children get older. Movement in big cities and particularly among poorer people may make identified cases hard to follow. The age at which we should be surveying populations is significant too. Surveying young adults with disabilities some years ago we found that the population was over-aged for finding any dystrophies, and although we felt we found most of the young adults with physical disabilities in two districts from multiple case searching of social, educational, and health sources, we surely failed to track some.

Diagnosis would seem to me to be very important. Looking at some Eastern European countries' databases they admit that diagnosing is never varied and quite often made very early on in the child's life, fixing children on a course which may be totally inappropriate to their abilities. The new ICF (World Health Organization) has many merits but it has some faults. Striving to get away probably from the old maligned medical model, the word 'diagnosis' does not appear in the index. Whereas, ironically in the twenty years from the original 1980 ICF, one of the advances in health care, the ability to say what is wrong or what is causing the disability, has developed greatly. Far fewer children now should be undiagnosed mentally retarded/learning disabled and the numbers will get fewer as the years go forward. The study of these individual groups of children has led to the ability to make suggestions about their management. But I deviate in thinking of management. What we're trying to think of is numbers: numbers of disabled children in our midst and whether we can state reliably that the numbers are changing. Databases are being set up which link obstetric data and child data. But issues round confidentiality, data protection, very often make them difficult to use. These are the real problems for those of us trying to collect accurate information about childhood disability. Until we have that, we shall not be able to prevent the too frequent and sometimes preventable neurodisabilities of childhood.

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