# Editorial

## The genetic testing of children

A young father has just been diagnosed as having myotonic dystrophy. The parents request that their 5 year old son be tested so that they can know if a similar fate awaits him. Geneticists dealing with such requests enter a clinical and ethical minefield. The recent report from the UK Clinical Genetics Society on testing in children (p 785 of this issue) is a welcome first attempt to provide a series of recommendations for clinical practice. These are based upon reports of current practice, ethical and legal principles, but not, of course, empirical evidence: there is, as yet, next to none.

One of the key recommendations in the report is that predictive genetic testing of children is appropriate only if disease onset regularly occurs in childhood or if there is an effective therapeutic intervention. It is also recommended that parents are counselled against testing children for adult onset disorders where no treatment is available and against testing for carrier status for recessive disorders. Ultimately, however, the report acknowledges that the decision about testing is an individual one, each case to be judged on its merits.

The report recognises that many health professionals besides those working within clinical genetics are involved in the testing of children and families, principally paediatricians and haematologists. The authors of the report conducted a survey of these and other groups to determine their views and practices in this area. Mindful of a low response rate, it would seem that attitudes and practices vary widely. Overall, paediatricians held more liberal attitudes towards testing children than did geneticists and their co-workers, with 79% of responding paediatricians believing that it is up to the family to decide whether or not their child or children should be tested, in contrast with 40% of those working within clinical genetics. Most geneticists disagreed with the proposition that testing in childhood for carriers of recessive conditions results in more responsible attitudes towards reproduction as an adult. The majority of paediatricians supported this proposition. There are no data to support either view.

The authors do not consider their report to be the last word on testing in children and call for further work. In particular they call for discussion and debate to try and achieve a consensus among health professionals. Given the range of views among health professionals on parental rights and the consequences of testing children, relevant research findings may be a necessary first step to achieving consensus.

We know that for other conditions the consequences of testing can vary quite dramatically. They are determined not only by the way in which testing is conducted but also by people's social, emotional, and economic resources.[1] While the main research interest will be to document the psychological effects of genetic testing in children, this needs to be qualified by the type and amount of counselling provided, as well as the resources of individual families. It will also be necessary to document the consequences of not meeting requests for testing. While prospective studies are planned, there is much information to be gleaned from the many children already tested. The families of such children could, for example, be approached to participate in case controlled studies of the consequences of testing.

Conducting testing using research protocols requires organisation, resources, and commitment. While the report acknowledges the usefulness of conducting psychological evaluation when children are tested, a firmer call for research is needed to provide the basis for evidence based policy in this area. Such a step was recently taken by the National Advisory Council for Human Genome Research[2] in considering inherited cancers. They stated that ". . . it is premature to offer DNA testing or screening for cancer predisposition outside a carefully monitored research environment." Perhaps the Clinical Genetics Society will consider a similarly robust policy statement for the testing of children under circumstances where there is no evident medical benefit. It might, for example, state that such testing should always be conducted within a research protocol that involves the collection of basic information on the psychological and social impact on children and their families.

Armed with the results of research we can look forward to the next report in this increasingly important area when policy can be built, not upon the shifting sands of "conjecture, anecdote, and prejudice", but upon the more solid rocks of empirical evidence. Hopefully this report will concentrate the minds of all who work in this area to achieve this end.

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1 Marteau T M. Towards an understanding of the psychological consequences of screening. In: Croyle R T, ed. *Psychosocial effects of screening for disease prevention and detection.* New York: Oxford University Press, 1994.
2 National Advisory Council for Human Genome Research. Statement on use of DNA testing for presymptomatic identification of cancer risk. *JAMA* 1994;271:785.