Editorial

Special service to special people

Professor Campbell Murdoch, Editor, MD PhD FRCGP FRNZCGP

My first introduction to people with special needs was to Billy, my wife's cousin, who has Down's syndrome. Billy is now in his mid-fifties, once thought impossible for 47 chromosomes, and lives in a community in Scotland. He always brought the house down at family weddings by his impassioned rendition of *'I'm nobody's child!'*

My next introduction was in 1972, when I was appointed as Medical Officer to Waverley Park Hospital in Kirkintilloch near Glasgow, where I had my first general practice.

Waverley Park had been the first private institution for the mentally handicapped in Scotland, and a review of the patient records made for some very intersting reading. Several old ladies had been 'patients' since 1908, and the diagnosis on admission was 'moral imbecile', which really meant that as simple girls they had given birth to a child out of wedlock. The files contained pious letters from outraged schoolmasters which demanded that such evil and infectious influences be removed from the community into an institution.

Time would tell that these old ladies had very little wrong with them in a physical or psychological sense; indeed one, who had been the personal maid to a succession of matrons, was given the town's version of a state funeral when she died in good old age.

In those days we were very much in the 'medical model' of dealing with people with intellectual disability. Doctors were part of a system which regarded such individuals as in need of classification as well as care. They were divided into overall groups such as imbeciles, morons and idiots according to their IQ, and into diagnostic groups such as mongols, microcephalics and spastics according to their physical attributes. They were held in huge institutions – the group where I was employed, Lennox Castle, had 2 000 beds and was housed in villas and cared for, mostly with great tenderness, by nursing staff. They all had impeccable medical care and one of my tasks was to carry out full medical examinations every six months. Lest we forget, they were in these large hospitals not for their own benefit, but so that the community would not be troubled by the presence of these strange, frightening, disinhibited and dangerous people who might have needs, aspirations and rights of their own.

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Today things have changed. The Lennox Castles and Cherry Farms have closed or are a fraction of their former size, and the scene has changed remarkably through the efforts of groups such as IHC. People with intellectual disabilities are now free to leave the 'security' of these sheltered villages, and, in spite of a few horror stories of people not being able to cope, the vast majority have found a much better life in the wider community.

The philosophy of IHC New Zealand is that people with an intellectual disability have the right:

- to be treated with respect and dignity;
- to have a say in their own lives;
- to live, learn, work and enjoy life as part of the community;
- to have support that meets their goals and aspirations;
- to be part of a family.

But have our professional attitudes changed? Articles published in this issue suggest that general practitioners have some way to go before we can claim to treat the intellectually disabled in the same way as our other patients. A general theme is the variable attitude on the part of general practitioners towards people with intellectual disabilities and how they should be medically supported. Particular issues are the problems of communicating with these patients, the reluctance of GPs to offer preventive medicine to those with intellectual disabilities and our lack of educational preparation to deal with these special people.

Our dealings with the intellectually disabled and their families usually start when the baby is born and the family has to bereave the loss of a normal child and accept the fact of having a child who is special. Bereavement is a process which takes time and it is important that the GP and Plunket nurse are able to provide support.

A study done in Scotland[1] a long time ago on the experience of moth-

ers giving birth to a Down's syndrome baby showed that in only one of two cases did the GP give positive support, and a replication of this study in New Zealand[2] came up with much the same conclusions – only half of the mothers felt that their general practitioner or Plunket nurse had been helpful to them after the birth.

After that less than satisfactory start, it is hardly surprising that further problems arise during childhood. A study of the opinions of 35 mothers of Down's syndrome children of 12 years and under in Christchurch and Dunedin, and their 28 general practitioners,[3] gave some further insight. This showed that the GPs had a significantly more pessimistic view of the problems of having the child than did the mothers. Both mothers and GPs gave the highest satisfaction rating for the GP's routine care of the child, but there was a highly significant difference in the satisfaction rating for vision and hearing assessment and in the area of the GP's taking the role of the overall coordination of the child's medical care. While it may be argued that this was a small study in a specific syndrome, another New Zealand study of 18-year-olds with disabilities[4] showed some dissatisfaction with consultations with GPs in relation to expectations of the efficacy of treatment and to the communication of the health professionals.

No one else but the general practitioner is going to take on the role of looking after the medical needs of the people with intellectual disability in New Zealand. The take home message seems to be that we have to communicate better with them and their families. This means taking time, and perhaps there is a strong case for better primary health care subsidies for this group. Above all there has to be time for preventive care, and the articles in this issue give important information as to the evidence that this is required.

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It is now nearly thirty years since I was 'shown' a case of a 37-year-old Down's syndrome lady in Lennox Castle Hospital and told 'this is how they go before they die in senile decay'. In my ignorance I thought she looked hypothyroid and her TSH was >50 international units. This led to a study[5] which showed a very high prevalence of hypothyroidism in a group of adults with Down's syndrome (12% v 1%), a finding which has been verified again and again. In 1999 I met Sharon, aged 40, who had been looked after very well by Winton Medical Centre for many years. She too was deeply hypothyroid.

The lesson is clear: prevention is not only better than cure, you have to perform preventive strategies before you can find the abnormalities to be corrected. In this area there are no good GPs and bad GPs, there are simply those who look and those who don't.

References

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