

The physically handicapped school leaver

“At root, it seems to me that the question of why we should be concerned with the plight of the handicapped is attitudinal. We should care because the handicapped are part of our humanity. Despite our good intentions and the passage of legislation, our efforts to help do not seem to work out as intended in increasingly sophisticated, complicated and technological societies when the child (whose emotional appeal for fund-raising is very great) emerges into the adult world. The rejection of the handicapped adult may be because ‘in some way they reveal to us who we are. We don’t want to look at their weaknesses’”¹

Paediatricians will be familiar with the expressed sentiments on fundraising. They will, sadly, also have become used to the fact that many of those they have cared for, throughout childhood, and through a good proportion of the paediatrician’s working life, have no job, no hopes, and a marginal existence; only a few of the less severely disabled will have developed a satisfactory adult lifestyle.

The extent of their needs has been documented many times, yet the report and its recommendations detailing this seems not to be widely available.²

As long ago as 1981 the Warnock report commented that the transition to adulthood was particularly difficult for the handicapped teenager: “The transition from school to adult life can be difficult for many young people. For those with special needs it is likely to be a period of particular stress”.³

At the same time Castree and Walker looked at a group of young adults with spina bifida and compared them with a similar group of cerebral palsied adolescents in Newcastle.⁴ They found that both groups had achieved a remarkable degree of independence in self care but the more severely handicapped of them had no work. Parents commented particularly on the poor contact with social services after leaving school and the difficulty they had in finding and mobilising help in a whole variety of areas. They also felt that the educational potential of their children was not realised.

This survey is referred to in a new supplement of the *Developmental Medicine and Child Neurology* series, ‘The health and social needs of physically handicapped young adults: are they being met by the statutory services?’¹ The booklet makes easy, graphic, and sorry reading, which is worth summarising.

Contact with the health services

“We have been told that it is hard for young adults to find speech therapists or other specialists to help them with feeding problems”. Hirst showed that 70–92% had lost touch with therapists, dentists, and doctors who had seen them at school.⁵

Poor mobility

Many young people lose their hard won ability to walk and develop contractures when they leave school and no longer have regular physiotherapy. It is difficult to know whether they are then helped by orthopaedic referral.

Housing adaptations, provision, and repair of aids and equipment

Several reports document what many will know from experience: that there is often a considerable delay before a family is well housed and before adaptations are made. These areas are usually outside the remit of doctors, but the provision of aids or appliances and the development of a joint aids store may not be. Robson, reviewing the work of the Newcastle young adult clinic held in their aids centre, found many unsatisfactory or worn out appliances and was able to offer much help with this and with wheelchairs. (Robson BJ. Report on the Newcastle young adult clinic (YAC) for the disabled. 1982. Unpublished report.)

Incontinence

Again there is little documented evidence relating specifically to young adults, although physically handicapped children have been shown to be in need of an adequate continence service⁶ in which the investigation of incontinence is undertaken and is related to other disabilities.

Dental health

Little is known about the dental health of physically handicapped adults. Some districts do establish clinics, but these often rely heavily on one interested specialist or are not continued when he moves or retires.

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Sexual and genetic counselling

Physically handicapped young people are less mobile than their peers; their knowledge of these matters is often rudimentary or faulty, they have little chance to 'pick up' information—whatever its quality, counselling is often poor or non-existent, and often the young people worry about the inheritance of their disability.

Maladjustment and psychiatric problems

These also occur at an increased rate sufficient to indicate that there is a need for access to psychiatric counselling for the young person and the family.

Education

Many children have lost much time and educational opportunity. One of the earlier documentations of this was that of Tuckey *et al*, 'Handicapped school-leavers, their further education, training, and employment'.⁷ Further education has become more widely available since then as employment has contracted. Nevertheless, facilities are highly variable and the would be student will be limited by geography more than anything else. Recent findings are detailed in 'Beyond the school gate'.⁸ Many authorities still do not recognise that they have a duty to provide for *all* young people who want continued further education between the ages of 16–19. It is worth recording that much helpful advice is available within the covers of 'After 16—what next?' published by the National Bureau for Handicapped Students.⁹ The related publication 'After 16: the education of young people with special needs' urges action.¹⁰

Income

The Spastics Society report says unequivocally, 'Two main factors contribute to the financial hardship of families caring for a handicapped dependant—increased family expenditure and reduced family income. Hyman¹¹ has estimated that disability in one member of the household could cost as much as 20–25% of the household income.' It is noteworthy that the Fowler proposals intend that where a household has more than one handicapped member benefits shall only be paid to one. Many believe that disabled households face great hardship in the future.

Employment

The disabled are less likely to be in employment and

even less likely to be in well paid, skilled work than their able bodied peers.

If open employment is difficult, sheltered employment, offering the benefits of a productive day with supervision, is a virtually non-existent option.

Social life

Like disabled people of all ages, young adults usually find their contacts reduced. In addition, these young people may never have acquired the social skills of those disabled later in life.

Why the problem?

In a word, then, the current situation is a shambles. At a time when the child is experiencing the oscillations and uncertainties of trying to emerge as an adult he is subject to constant threats to his supposedly independent status in that role. Those who have supported him through childhood have no statutory obligation to do so, indeed statutory demands on their time are heavy; parents are aging and finding much cause for anxiety. Health and social services fail him.

The Spastics Society contends this is for three reasons:

- (a) Poorly organised services and few trained personnel.
- (b) Poor coordination and communication between health and social services with little knowledge of the needs of the handicapped—the data base is usually absent.
- (c) A poverty of information available to the handicapped person.

Possible solutions

One cannot quarrel with these findings: the evidence is too strong. Does one agree with the recipe for change, assuming that no concerned person would defend the status quo?

A district handicapped adult team is proposed, available to offer advice on all the matters detailed above, together with a young disabled adult clinic, in service training for involved professionals, and a registry. It is further proposed that local surveys of the numbers and needs of disabled populations should be undertaken. Finally, the team should include a physician with expertise in the management of handicap, a 'broader-based specialist in adolescent-adult handicap'—that is, a separate specialist from the consultant in neurological rehabilitation or medicinal disability.

How realistic is this? An 'at risk' register would be a useful data base, although how we should use it is

not clear. The Southampton group have shown a great deal of stress in such families and suggested that rapid intervention (more support services at home with intermittent relief) would help if it were provided at crisis times.¹² Who would man such a computer register? What would be the chains of communication or command that would allow a flexible response from the several statutory bodies to be called up?

The young adult clinic has been shown to work. It is not advocated in so many words in an important new report 'Physical disability in 1986 and beyond' in which a section is devoted to the young adult.¹³ But it is acknowledged that there should be an assessment centre and referral to an appropriate consultant should be made. This is the nub of the matter, perhaps.

As far as I know, the excellent umbrella of paediatric services found in most parts of the land did not arise spontaneously nor yet from isolated ventures by a variety of professionals. It arose from the work of concerned paediatricians who regarded it as their brief to establish what were considered necessary features at various times.

The Royal College of Physicians is rightly exercised by the fact that such services for disabled adults are lacking. They are a 'deprived population' able to call on few specific facilities and a paucity of consultants with specific expertise in the management of their disability problems (there are perhaps 50 of us in the United Kingdom). The plight of teenagers is but one face of this problem.

The college acknowledges that the UK is engaged on an important but unplanned experiment 'to set up an effective care service for the physically disabled without a substantial specialty of rehabilitation'. It goes on to recommend the equivalent of 10 sessions devoted to this per district, split between two to three consultants, and at regional unit level two full time consultant posts. The report acknowledges that the health service needs to provide information, registers, key workers, committees, handicap teams as well as continence advisers, wheelchair clinics, and disabled living centres. Is it reasonable to expect these to arise separately and yet cohesively without the appointment of a consultant majoring in this commitment? It seems quite

unrealistic for the Spastics Society to look for a subspecialist for adolescents when the corresponding adult specialist is still missing.

There may be the opportunity to create a few more consultant posts shortly. Perhaps paediatricians would feel able to persuade their adult (!) colleagues that one such appointment to a district and certainly to a teaching hospital could be catalytic in profoundly changing the current dismal situation of their teenage patients.

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