Archives of Disease in Childhood 1993; 69: 399–402

CURRENT TOPIC

Physically handicapped school leavers

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Twelve years ago I wrote an annotation for this journal entitled 'The handicapped school leaver'.[1] I pointed out what many knew and Warnock has so clearly stated – that 'the transition from school to adult life can be difficult for many young people. For those with special educational needs it is likely to be a period of particular stress'.[2] I lamented the loss of an extra year in education which disabled children formerly enjoyed, their lack of educational opportunities, employment, training, pre-employment and social skills, the paucity of suitable transportation and mobility, of appropriate day care, and housing.

Has anything changed? Is it worth you, the reader, reading on?

It seems, for many young people, nothing has changed. Similarly, many paediatricians remain anxious with good cause. They see what Peter Swain described as a void opening up before their maturing patients, a void down which they will hurtle.[3] This view, of the almost total lack of any coordinated services for young adults comparable with those so ably put in place by community paediatricians, for children, is widespread. But there *are* some innovative schemes. A few community teams are in place in some parts of the UK with a brief for young physically handicapped adults, although there is little knowledge of their existence.

The task: targets for the young person

THE PROBLEMS

The problem of how to achieve the targets remains, though not entirely as it existed in 1981: now further education for these young people is well developed in many areas of the UK. The subsequent problems of higher levels and longer periods of unemployment than able bodied peers remain, exacerbated by the current economic climate in which some 17% of all young adults are unemployed, including those with higher qualifications. There has also been little building of public housing in the last decade so that the young person's desire to leave home is often thwarted and the progression to responsible adulthood is impeded not only by their impairments and disabilities, but also by the handicaps imposed on the individual by an economy in recession. Nevertheless, we have to assume that recession will lift and that young adults, including physically handicapped ones, need to be prepared. They need to acquire skills.

THE TASK

Hardoff and Chigier describe the path travelled by the adolescent towards maturity as one when four major developmental tasks have to be accomplished.[4] They must: (i) consolidate their identity, (ii) achieve independence from parents, (iii) establish adult relationships outside the family, and (iv) find a vocation. The young person's medical condition may have an impact at three levels: impairment, disability, and handicap.

Diseases and impairments

Disease may still be active (as in juvenile arthritis, muscular dystrophy) or its effects may persist (cystic fibrosis, diabetes mellitus) or produce sequelae. The neurological deficits of conditions such as spina bifida remain; impairments such as incontinence have daily impact and without regular review may lead to renal failure. Those who have sustained brain injury may be learning, but the rate at which they learn may remain slower than that of their peers. They may also have to contend with memory deficits, with visuospatial and possibly with sequencing difficulties. Many of those with epilepsy have poorly controlled fits restricting work, leisure, and mobility.

Disabilities abound

The numbers of children and adults with various disabilities in the UK have been analysed by age, by severity of disability (1–10), and by type in the Office of Population Censuses and Surveys (OPCS) report of 1988.[5] Further analysis of these results for the younger adults up to the age of 29 years showed that there were some 340 000 young people between the ages of 16 and 29 years with a disability severe enough to be included in the survey, constituting about 5% of all disabled people and 2·5% of their age group.[6] Few are in residential accommodation but, of those who are, more than half of these are very severely disabled.

The disabilities associated with neurological diagnoses in the younger adults who are severely disabled are many; frequently one diagnosis leads to many disabilities. Conversely, different diseases may lead to a common disability (for instance, mobility may be impaired by arthritis, cerebral palsy, or cystic fibrosis).

Table 1 Prevalence (%) of disabilities in young adults (from Parker and Hirst[9])

Moderate or severe disability	Impairment*			
	Physical (n=65)	Mental (n=82)	Multiple (n=144)	All (n=291)
Continence	2	–	40	20
Mobility	57	2	50	37
Behaviour	6	38	48	36
Speech	2	52	76	53
Personal care	20	13	72	44

*Percentages do not add up to 100 because of multiple disabilities. A later study gives evidence of the experience of multiple disability at all levels of severity. Four hundred young people aged 12–20 years were drawn from the OPCS sample[10]; 72% of these had more than one disability and almost half (46%) had more than two.[11]

Handicap is the final common pathway of the interaction between disability and the surrounding physical, social, and psychological environment. For many young people with neurological diagnoses and their families this handicap is major.

Table 1 gives the prevalence of some common disabilities and impairments and table 2 gives the incidence and prevalence of various diseases in young adulthood (as far as known). Table 3 indicates the practical problems resulting in dependency in various groups of young adults studied by three groups.

Table 4 is one of many tables that can be constructed to illustrate potential service requirements throughout life arising from a diagnosis in childhood (in this case cerebral palsy). Demands can be highly variable but the table is given to illustrate that help is required over many years and in many domains, some specialist to a disease, some more representative of what many would require in transitional years. There is little evidence of specific services in place throughout the health districts of England and Wales, although Edwards and Warren in 1990 found that services were said to be present in some form in 35%.[7]

Table 2 Diseases leading to disabilities in young adults

Disease	Incidence	Prevalence in young adulthood	Life expectancy
Cerebral palsy	2/1000 live births; about 90% survival to adulthood	200/100 000	Probably normal except with epilepsy and other concurrent expectancy reducing conditions
Spina bifida	Variable and fallen dramatically; 60% survival to age 21 (changing)	2/100 000 and declining cohort	Unknown
Thalidomide induced limb deficiency	Cohort	Cohort	Unknown
Muscular dystrophy (Duchenne)	1/8000 or more per live births	90/100 000	To 20 years, rarely 25 years; varies with type
Cystic fibrosis	1/2500 per live births	Increasing by 100 over 15s per annum	25% alive at 30 years; changing
Juvenile arthritis	1/1000		Probably slightly reduced (as adult inflammatory arthritis, due to amyloidosis)
Spinal injury	3·5–8/100 000		Unknown, but probably survivors of initial phase survive long time
Head injury	26/100 000 moderate to severe	Unknown; estimated at about 1/1000	Probably 50 years for survivors of initial phase without major impairments such as epilepsy
Multiple sclerosis	Variable geographically. Rare before puberty, peaks at age 30	About 80/100 000; higher in Scotland	Reduced

What can be done?

When I wrote in 1981 I had managed to locate some independence training centres and those run by voluntary agencies were particularly evident. There was also some direct placement in work where special careers' officers were available. For practical purposes, sheltered employment was irrelevant and day care generic only with no facilities for young people. Younger disabled units were seen as an option

Table 3 Proportions (%) of young people with disabilities who depend on help with activities of daily living

Study*	Mobility	Feeding	Dressing	Washing	Toileting
Thomas *et al*[12]	87	52	65	NFA	64
Hirst[13 14]	58	49	76	85	62
Paediatric Research Unit[15]	28		†		

NFA=no figures available.
*Thomas *et al*: sample of 104 young adults in two contrasting health districts; age range 18–25 years.[12] Hirst: sample of 291 young adults draw from the Family Fund register from all parts of England, Wales, and Scotland; age range 18–22 years.[13 14] Paediatric Research Unit, Exeter: sample of 383 young adults living in Exeter health district; age range 16–25 years.
† Overall proportion 39% needing help with personal care.

Table 4 Cerebral palsy: possible service requirements (dependent on a range of variable symptoms)

	Disease				Health service provision		Disability: other service provision						
	Prevention	Investigation	Medical treatment*	Surgery	Rehabilitation	Support†	Housing/ adaptations	Education	Vocational assessment for work	Transport	Leisure	Social service/ carer support	Benefits
Birth	0	+	0	0	+	0	0	0	0	0	0	0	0
Child	0	+	+	+	++	+	±	+	0	±	0	±	0
Teenager	0	0	+	+	+	+	+	+	++	++	+	+	+
Adult	0	0	+	0	±	+	+	±	+	+	+	+	+

*To deal with problems of epilepsy and spasticity. †For problems with continence and wheelchair and nursing provision.
Service requirement needed: 0=none, ±=possible, + =yes, + + =major.

(albeit not a particularly welcomed one) for respite or residential care.

What is on offer now? Thinking is clarified somewhat by the International Classification of Impairments, Disabilities, and Handicaps terminology. For those with active disease, or persistent impairment, adult medicine has something to offer: the young adult with inflammatory arthritis needs disease modifying drugs and the services of a rheumatology department, the one with epilepsy will almost certainly need up to date prescription of anticonvulsants tailored to size and lifestyle from an appropriate hospital physician. Those with cystic fibrosis continue to need expert management while those with spina bifida may benefit from being taught intermittent self catheterisation or may be referred for bladder surgery.

But to base the young person's care with a specific consultant, in hospital, may not be in the young person's best interest when their main task is a transitional one, when disabilities have to be replaced by skills, handicaps have to be reduced, and independence and autonomy have to be fostered. The young person is probably best served by a community based multidisciplinary team, along lines familiar to paediatricians. The team has to be client centred and goal orientated, goals being negotiated with the young person. Often there have to be improvements in many fields including health maintenance, self care, mobility, domestic skills, and those which enhance the person's interaction with society. These have to be coordinated, and planned to fit with training, with availability of suitable housing and work and with the patient's desire to progress to a higher level of function.

The following case history illustrates some of the areas in which such improvements have to be made by the young person. John referred himself to the young adult team in July 1989. He was 21 and had cerebral palsy with variable spasticity and major involuntary movements, being dependent for all activities of daily living, using an outdoor manual wheelchair and an indoor electric wheelchair. His speech was difficult to understand, especially to unfamiliar listeners. In an attempt to communicate better, he had borrowed an old communication aid, but rarely used it. At that time he lived in a social services residential establishment and spent some time each week at a local resource centre specifically for young people with physical disabilities. His main interest was in computers (he had his own), and he also liked photography, socialising, and the cinema. John had an outgoing personality, but getting out was a problem for him as he was dependent on others for transport and communication.

At John's initial visit to the team it was felt that he needed to develop his communication skills with the help of the speech and language therapist. He also agreed to work with the physiotherapist to look into better and more supportive seating; residential staff had to be trained to help John maintain his mobility. At this time the young adult team had no occupational therapist and no psychologist in post to help John increase his confidence and social skills. It was therefore decided time should not be lost and other needs addressed: the social worker would be involved in supporting John in his application to do computing at a residential college of further education and in looking at his longterm living arrangements. The senior clinical medical officer arranged a chest radiograph as John appeared to be aspirating due to his pseudobulbar dysfunction, and sought neurological advice in the hope that there was a new medication available for his wild and uncoordinated involuntary movements that were a source of distress.

Over many months much help was given. The speech and language therapist assessed John's need for a communication aid and raised funds to obtain one. She and John visited many public places, including pubs and restaurants, to encourage him to use it proficiently. The physiotherapist helped John find and acquire an excellent indoor electric wheelchair with good seating and trained him in its use. The occupational therapist who joined the team later worked with John to ensure that he was able to manage his domestic chores and feed himself in the sheltered accommodation found by the social worker for him.

Unfortunately, John's application for further education was turned down and his new medication for involuntary movements produced an unacceptable level of side effects. Nevertheless, after almost two years of working with the team John had become a confident, articulate and, within the bounds of his condition, capable young adult.

A few teams have been developed in response to this need. One of the earliest in the UK was led by Robinson, an orthopaedic surgeon in Newcastle who did a great deal to help young adults with spina bifida. Recently, other models have come on the scene. Some have an educational bias, some are centred round charismatic individuals. Some represent the only rehabilitation facility in a district, some exist within the infrastructure of rehabilitation services recommended by the report of the Royal College of Physicians.[8]

Two of these have been evaluated systematically with grants from the Nuffield Provincial Hospitals Trust. These teams (in Stoke on Trent and Leeds) have certain features in common. They were both set up by consultants in rehabilitation medicine who had helped establish the recommended range of services including acute inpatient rehabilitation facilities. Both consisted of a stable team which included physiotherapist, occupational therapist, speech therapist (Leeds), nurse (Stoke), psychologist, and doctor (senior clinical medical officer in Leeds, senior registrar in Stoke), and social worker with access to a range of good services. Both had links with careers, education, and employment services. The Leeds team had (for a time) the opportunity of obtaining vocational assessment for its clients. The Stoke team interacted with several other community teams; the Leeds team found an interested neurologist with particularly relevant expertise.

Evaluation of the Stoke team revealed high user satisfaction with the service and that the young people gained access to much equipment, resources, and services that they needed. The Leeds survey showed the same effect, that the team provided an easily identified focus for obtaining necessary equipment and access to services. In its first two years, 220 interventions had been made for 68 patients, the number of such interventions per patient exceeding those for young patients not contacting the team, even over a short time.

Our impression is that young adult teams result in much improved health and health maintenance skills and that they help the young person mature and gain abilities. They reduce the anxieties of carers. They probably help prevent deterioration (although we are struggling with outcome measures to monitor this). But their ability to help is sadly limited by poor access to housing, training, appropriate daytime activity, or work.

Perhaps, if I return to your pages in another 10 years, there will be a more successful story to tell but, in the meantime, if paediatricians will join their colleagues in rehabilitation medicine in urging purchasing authorities to invest in community young adult teams, the groundwork laid by paediatricians will have some chance of producing healthy, integrated young adults. In Scandinavia, young physically handicapped people enjoy what they themselves describe as 'a good quality of living'. The means are available for us to do the same for our young patients.

A health assessment bulletin, produced by our department has been distributed by the NHS Management Executive to regional authorities and is available from: Department of Health, NHS Management Executive, Research and Development Division, Quarry House, Quarry Hill, Leeds LS2 7UE.

The author is grateful for the help of Mrs S Guthrie and Leeds Young Adult Team.

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