

PAPERS AND SHORT REPORTS

Health care of physically handicapped young adults

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Abstract

Little is known about the health needs of physically handicapped young adults after they become too old for the paediatric service. To assess these needs 104 young people with physical handicaps were given a medical examination and interviewed. They had diverse physical handicaps, many of which were rare (41 subjects); 45 had cerebral palsy and 18 spina bifida. Mental handicap (42 subjects) and a need for special education (28) were also diagnosed. The state of health of all subjects was generally poor. Sixty one subjects had contractures of the lower joints and almost a quarter contractures of the upper joints; 26 had deformed feet. Consequently, many subjects (41) could not walk; only 13 could walk without difficulty. Urinary and bowel incontinence were prevalent (58 and 55 subjects, respectively) and with contractures and pressure sores resulted in skin problems (35 subjects). Kyphoscoliosis was present in 30 subjects, particularly those with spina bifida (10 out of 18), of whom one third had respiratory problems and almost half cardiac problems. Thirty one subjects had epilepsy. Many subjects (49) had difficulty communicating or some visual defect (27).

Although over half the subjects had health problems that were severe enough to warrant intervention, less than a third were receiving any form of regular hospital care; regular contact with physiotherapists, speech therapists, and dentists was also poor. Moreover, the original diagnoses and prescriptions had not been reviewed regularly. Teams for handicapped adults should be set up in all district health authorities to provide a clinical and coordination service for all adults with physical and mental handicaps.

Introduction

Over the past 10 years services for handicapped children have

developed considerably. In 1976 the Court report recommended that district handicap teams to be set up to cater for the health needs of handicapped children,¹ and more recently the 1981 Education Act emphasised the educational needs of such children. By contrast, services for handicapped young adults have received little attention.²⁻⁴ Though recent research focused on the decline in contact of handicapped young people with the health services⁵ information about the state of health of these people is lacking. We report the results of a study to assess the state of health of young physically handicapped adults and to determine whether their health needs are met by the statutory services.

Method

We selected two health districts for the study; one was in north west London, representing an urban health authority, and the other was in south Buckinghamshire, representing a semirural health authority. We identified young people aged 18-25 with moderate and severe physical handicaps from several sources, including the records of the district health authorities and the district handicap teams; contact with the local departments of social services and occupational therapy, day centres, and charitable organisations; and the register of the Joseph Rowntree Trust Family Fund. Of an initial list of 271 names, 114 subjects were excluded because they had died, had moved away, or had a primary handicap such as a sensory loss or emotional problems that were not within the remit of the study. Fourteen subjects refused to take part, and a further 32 could not be traced. We therefore interviewed 111 subjects, an interview rate of 71%, and gave 104 of them a medical examination. Importantly, we could locate only one in three of the subjects seen in the London area from the records of the district health authority.

A full medical history was taken and each subject examined by one of us; a social psychologist interviewed the subjects together with the person who cared for them. When possible (102 cases) the interviews and examinations took place at the subject's home.

Results

On examination the 104 subjects fell into three diagnostic groups: 45 had cerebral palsy (36 spastic, nine athetoid); 18 spina bifida; and 41 one or more of a wide variety of conditions, including Still's disease (seven), multiple sclerosis (one), muscular dystrophy (one), poliomyelitis (one), Morquio's syndrome (one), and congenital limb deformity due to thalidomide (one). Many of these conditions are rare but contributed appreciably to the sample. One third of the subjects (42) were also mentally handicapped (intelligence quotient (IQ) 30-70) and a further quarter (28) had an IQ of 70-99, which is

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considered to be the range in which special education is needed. When a modified form of the Pultibec system was used to measure the severity of disability^{6,7} 16 subjects were mildly handicapped, 48 were moderately handicapped, and 40 were severely handicapped.

HEALTH CARE

Table I shows the main physical findings. The classification of subjects as obese or emaciated was a clinical judgment and reflected a severe problem. Overall, a quarter of the young people were obese, although obesity was primarily a problem for those with spina bifida (eight subjects, 44%). By contrast, emaciation was a particular problem for subjects with cerebral palsy (seven, 15%) and in several cases resulted from difficulties in feeding. One third of all subjects had kyphoscoliosis. A third of the subjects with spina bifida had respiratory problems such as a greatly reduced peak flow, and nearly half had cardiac problems with dyspnoea, oedema, raised blood pressure, and increased pulse rate at rest; these problems seemed to be a consequence of kyphoscoliosis and severe obesity, which severely distorted the architecture of the chest.

Overall, 43 subjects could not walk at all and 19 could do so only with aids; only 13 could walk without difficulty. A quarter of the subjects had contractures in the arms and over half had contractures in the legs; most subjects with cerebral palsy had fixed contractures at the hip, knee, and ankle. Notably, one third of subjects with athetosis had fixed contractures in legs, though these are generally said not to occur. A quarter of the subjects had severe deformities of the feet, which in our view was often due to their posture and to a lack of supervision of their seating position (figure).

Although none of the subjects were classed as visually handicapped, a quarter had appreciable problems of visual acuity and 24 had some abnormal eye movements, either a squint or nystagmus. Problems with hearing were less common, occurring in eight subjects.

Altogether 58 subjects were incontinent of urine and 55 had bowel incontinence or constipation. As a consequence of incontinence, fixed contractures, and pressure sores three quarters of the subjects with spina bifida had skin lesions when examined. While those caring for the subjects were often anxious about ulcers and broken skin on the feet and legs the subjects themselves seemed to have little understanding about the importance of hygiene in preventing deterioration of the skin.

Many of the subjects with cerebral palsy reported that their physical condition had deteriorated after they had left school; they had become less mobile and their contractures more fixed. They claimed that their overall physical state had not been reviewed since they had left school and changes in their motor performance had not been assessed. In many cases the physical difficulties had progressed so far that deciding on the most realistic way of dealing with them was difficult. Communication was also a severe problem for 27 subjects (60%) with cerebral palsy. Speech therapy would have been beneficial to remedy the problems of articulation and alleviate difficulties with eating and swallowing experienced by 57 of all those interviewed, yet only 14 received speech therapy regularly. This disparity was particularly apparent for the subjects with physical and severe mental handicaps. Of these, 37 subjects were considered to require speech therapy, yet only 10 regularly received it.

The subjects with spina bifida were striking because of the enormity of their problems: short contracted legs, obesity, kyphoscoliosis, poor control of the bowel and bladder, and care of the skin were problems that needed attention. Two young people in London had unrepaired primary lesions. One of these lesions was infected and leaking cerebrospinal fluid at the time

TABLE II—Number (percentage) of young handicapped people having regular contact with paramedical services

	Physiotherapist	Occupational therapist	Speech therapist	Dentist
Spina bifida (n=18)	2 (11)	0 (0)	1 (6)	9 (50)
Cerebral palsy (n=45)	17 (38)	10 (22)	10 (22)	27 (60)
Other (n=41)	10 (24)	5 (12)	4 (10)	25 (61)
Total (n=104)	29 (28)	15 (14)	15 (14)	61 (59)

of our survey; the young man had not received any direct medical attention for three years, and six months after the study he died. The other (subject) sat well forward in her wheelchair with a cardboard box protecting the lesion. As a consequence of her flexed posture she had developed gross oedema of the legs.

Health monitoring was particularly poor. Almost a third of the young people were taking anticonvulsant drugs; in one instance, the prescription had not been reviewed for 15 years, and in others for at least 10 years. Because of the dose of these drugs it was doubtful whether they contributed appreciably to the control of seizures. Many subjects were also taking tranquillisers, although the reason for their initial prescription was often difficult to ascertain.

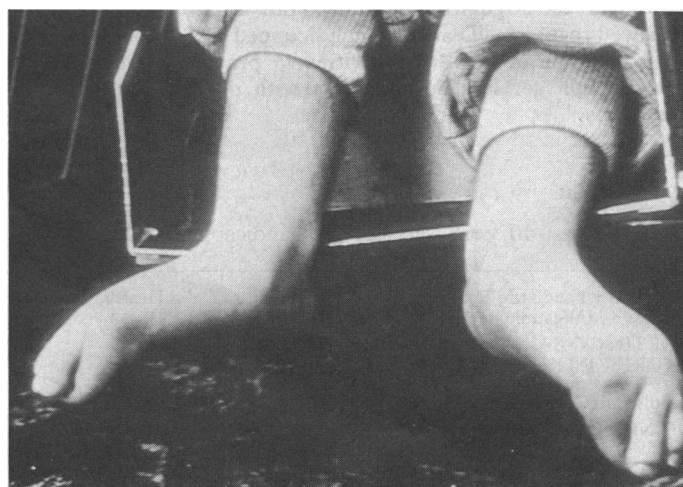
CONTACT WITH THE HEALTH SERVICES

The regular care that the subjects had received from hospital declined sharply after they left school. Though two thirds of them had received regular hospital care before the age of 18, only 29 continued to receive it. The decline was particularly apparent in the group with spina bifida: 17 of the 18 subjects had received regular hospital care before 18, but only seven continued to do so. Overall, 42 subjects had not seen any hospital doctor in the previous two years. Most of them consulted their general practitioners "on demand," usually for repeat prescriptions, with the result that one third of them had not seen their general practitioner for over a year and a further one in six for over five years.

The discrepancy between the need for health care and its provision was considerable. Overall, 61 (59%) of the subjects (27 (60%) with cerebral palsy and 14 (79%) with spina bifida had health problems that were severe enough to warrant intervention but were not being attended to by the health services. For example, one subject, a young man, presented with severe problems of health and communication that seemed to us to require considerable attention. He had severe dental caries because he tended to bite the fingers of the attendants who tried to clean his teeth. He could not communicate and often bit himself, resulting in three severe callouses on his arms, which often bled. He had progressive kyphoscoliosis; fixed hips, knees, and ankles; and broken skin on his feet, where the toes overrode each other (figure). In addition, he had epileptic fits even though three anticonvulsant drugs were currently being prescribed. Although he received daily help from two community nurses, regularly attended a day centre, and received support from social workers, his health and social problems persisted untreated. Another example was a young man with spastic diplegia, though his problems were less severe; although he had undergone 13 orthopaedic operations on his legs, flexion of his hip was limited and he could not sit with his body flexed on his thighs at a right angle. Consequently

TABLE I—Number (percentage) of young handicapped subjects with moderate and severe health problems

	Cerebral palsy (n=45)	Spina bifida (n=18)	Other (n=41)	Total (n=104)
Emaciation	7 (16)	1 (6)	3 (7)	11 (11)
Obesity	2 (4)	8 (44)	10 (24)	23 (23)
Cardiac problems	4 (9)	8 (44)	7 (17)	19 (18)
Respiratory problems	4 (9)	6 (33)	7 (17)	18 (17)
Kyphoscoliosis	13 (29)	10 (56)	8 (20)	30 (29)
Lower joint contractures	32 (71)	12 (67)	17 (42)	61 (59)
Deformities of the feet	14 (31)	7 (39)	6 (15)	26 (25)
Problems with coordination of hands	36 (80)	3 (17)	28 (68)	67 (64)
Problems with skin care	14 (31)	13 (72)	8 (20)	35 (34)
Bowel problems	25 (56)	15 (83)	15 (37)	55 (53)
Bladder problems	24 (53)	17 (94)	17 (42)	58 (56)
Visual defects	15 (33)	3 (17)	9 (22)	27 (26)
Hearing defects	3 (7)		5 (12)	8 (8)
Speech and communication problems	27 (60)	3 (17)	19 (46)	49 (47)
Waking at night	25 (56)	6 (33)	18 (44)	49 (47)
Epilepsy	15 (33)	4 (22)	12 (29)	31 (30)



Severely deformed feet of one subject, showing overriding toes.

he was unable to transfer his weight and could not toilet himself. Physical examination suggested that this problem might be overcome with physiotherapy, which we arranged.

Contact with the paramedical services was also poor: only 29 subjects had regular contact with a physiotherapist and 15 with a speech therapist (table II). A third of the subjects no longer saw a dentist regularly. Only two subjects were receiving help from a psychologist, which in both cases was paid for privately. The subjects with spina bifida were the least likely to have regular contact with the paramedical services (table II).

CARERS

Most subjects (98) lived with their parents or a close relative, and most of the carers were in their late 40s and early 50s (range 42-76). Twenty three of the carers had a disabling illness, including arthritis, back problems, chronic asthma, and nervous and depressive illnesses; and 18 of these thought that their illness severely limited their physical activities. The workload of the carers was enormous: 49 subjects needed attention at night, 52 needed to be washed and lifted in and out of the bath, 57 needed to be dressed, and 42 needed to be fed, yet only 25 families received any practical help in the home. Regular help, when it occurred, came generally from friends (15 families) and relatives (25 families) rather than from the statutory services (12 families).

Discussion

Many people in the study had severe health problems that were not being treated. We believe that these problems arose from poor early diagnosis, the changing nature of many of the chronic conditions, and clinical deterioration owing to a decline in care after the subjects left school.

In several instances the diagnosis was clearly incorrect or only partially correct. Without an accurate diagnosis it is difficult to recognise health needs and provide services accordingly. For example, one young man who was known to the health authority as having cerebral palsy was in fact primarily mentally handicapped. His father told us that cerebral palsy had been diagnosed when his son was in the neonatal ward and had not been revised, although his son was now a teenager. If his mental handicap had been correctly diagnosed he would have had more services available to him through the community mental handicap team and his condition would not have been regarded as primarily one of physical handicap. In another example a girl had been diagnosed at the age of 5 as having sensorineural hearing loss, although her dwarfism was never diagnosed. The hearing loss and the congenital abnormality had never been firmly linked, and when we saw her as a teenager neither she nor her younger sister, who had the same disorder, had been given hearing aids. The failure to revise the initial diagnosis meant that her problems had never been fully investigated and therefore remained untreated.

Though many of the primary handicaps are not progressive, many subjects examined showed signs of physical deterioration. For example, subjects with athetosis said that they had not had contractures when they had been at school; few of them, however, had continued to take regular exercise or have physiotherapy after leaving school and consequently had developed contractures and postural deformities and were no longer able to stand. In other cases of cerebral palsy additional degenerative disorders that needed attention, such as osteoarthritis, had probably developed, and contractures also had become more severe. In the subjects with spina bifida orthopaedic, cardiac, respiratory, and dermatological complications were common. One young man with Morquio's syndrome had developed compression of the spinal cord after leaving school, which was not recognised until we carried out our study.

General practitioners should clearly pay more attention to the needs of young handicapped people, but, given the complexity of many handicaps, specialist back up services are needed. A recognisable district service is clearly needed to provide continuing health care for physically handicapped young adults and to ensure that health care is integrated with their social care and further educational needs. Most district handicap teams do this for

children who have physical and other handicaps, whether or not they are also mentally handicapped, until they leave school. Thereafter, community mental handicap teams are available to meet the health, social, and educational needs of mentally handicapped people but no specialist health and coordinated services are currently organised for people who are only physically handicapped.

Furthermore, an important weakness of the community mental handicap teams lies in their lack of resources to deal with major physical problems. For example, although the number of nurses, therapists, and clinical psychologists specialising in mental handicap in these teams has increased since 1982,^{8,9} the medical representation has declined. We found that young people with both physical and severe mental handicaps were three times more likely to have severe health problems requiring medical attention.

We suggested previously that handicapped adult teams should provide health care for both physically and mentally handicapped people after the age of 18, and we believe that these teams could evolve within the existing framework of the community mental handicap teams.^{4,10} In 1986 the Royal College of Physicians proposed that the needs of the disabled should be catered for by district medical disability services, whose function would be primarily medical.¹¹ In addition to providing a clinical service, however, we think that the proposed handicapped adult team should provide physiotherapy, speech therapy, and a psychological service and deal with the social aspects of handicap, including sexual and genetic counselling, housing, finance, and daytime placement. Though the team proposed by the royal college would function autonomously, we envisage that our proposed handicapped adult team would link up with the existing district handicap teams, the health services in schools, local social services departments, and local education authorities.

Handicapped adult teams already exist; Newcastle upon Tyne, for example, has a clinic for disabled young adults, which has clinical, advisory, and coordinating functions.¹² Operating on a weekly basis, it has the services of an orthopaedic surgeon, a physiotherapist, an occupational therapist, a disablement resettlement officer, and an information officer, and the clients have made considerable demands on both the medical and the welfare services offered. Thus the clinic has proved to be successful, is busy, and serves a definite need. Though such local innovations are excellent, they usually operate on a shoestring budget, which is often funded by charitable donations, and they are too few to meet the needs of all physically handicapped adults. An agreed policy is needed whereby new, adequately funded clinical and coordinating handicapped adult teams are created in each district health authority.

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