Continuity and change in medical care for young adults with disabilities

GILLIAN PARKER, BA, PhD
Research Fellow

MICHAEL HIRST, BA, PhD
Research Fellow*

Social Policy Research Unit, University of York, Heslington, York

The medical care and supervision of young adults with disabilities has long been cause for concern. Over 20 years ago the British Council for Rehabilitation of the Disabled noted that medical services, although individually good, could not easily provide continuing help during the transition between school and adult life [1]. In 1976, the Court Report on child health services pointed out that young people with disabilities were probably less supported during adolescence than at any other time [2]. More recently, the Children's Research Fund pointed to reduced contact with the health services and the lack of practical support during the transition to adult life [3].

Very little is known about what happens when young people with disabilities move from child to adult health services. Some research has touched on the lack of continuity of medical care [4-7]. Other studies have focused on unmet needs, including the medical and health needs, of young disabled adults [8,9]. This paper presents the results of a recent survey of young people with moderate to severe disablement. The survey aimed to find out what happened when they left school or became ineligible for paediatric care and to assess carers' views and preferences about the young adults' ongoing medical care and supervision.

Methods

Sample

The sample of young people was drawn from the register of families helped by the Family Fund. The Family Fund is administered by the Joseph Rowntree Memorial Trust on behalf of the government and distributes about £6 million a year to families caring for a severely disabled child [10]. The register is the most comprehensive record of severely disabled children in the UK although there is no entirely satisfactory method of assessing its representativeness [11].

To investigate the transition from childhood to adult life, 291 families with a severely disabled young adult were interviewed in April 1983. All had previously participated in a postal survey of over 1,100 families with a young disabled adult who lived in England [12]. The findings presented below are drawn from the interview survey. Data were obtained from a structured interview with the young adult's main care-giver, in most cases his or her mother. A response rate of 92 per cent was achieved. Full details of the research design, sampling frame and methods are given elsewhere [13].

Measures

Carers were asked about past and present medical care for the young person, about changes in medical care after the young adult had left school or reached sixteen, about felt needs for medical supervision, and about difficulties with arrangements for their son's or daughter's medical care. Information was also collected on the young adult's degree of deficiency, difficulty, or disturbance in performing activities in six areas of everyday life: continence (control of excretion); mobility (walking, climbing); behaviour (personal, social); speech (talking, expression); personal care (eating, washing, dressing); and education (reading, writing, counting). In each case degree of disability was rated from no problem, through mild and moderate to severe problem. Information on disablement was also used to classify the young adults as mentally or physically impaired. The term 'multiply impaired' covers those who were both mentally and physically impaired.

Results

Characteristics of the young people

The young people were aged 18 to 22 but almost half were 18 and most of the remainder were 19 or 20 years old. Forty-six per cent (133) were women. With three exceptions, where the family was headed by a grandparent, all young people lived with their parents: 78 per cent (228) with both parents and 21 per cent (60) with just one
parent (55 lone parents were the young adult's mother and five the father). One in five (61) were still at school; the remaining young people had left school during the three years prior to the survey and, on average, 20 months had elapsed since they had done so.

Twenty-five per cent (73) of the young people were described only as mentally retarded or brain damaged; a further 21 per cent had Down's syndrome (62), and 20 per cent had cerebral palsy (57). Eleven per cent (33) suffered from spina bifida. The remaining 23 per cent suffered from a wide range of disabling disorders including muscular dystrophy, autism, epilepsy and vaccine damage, but none of these had an incidence of more than 3 per cent in this sample.

Table 1. Incidence of disabilities in young adults.

| Moderate or severe disability | Impairmenta |   |   |
|------------------------------|-------------|---|---|
|                              | Physical %  | Mental % | Multiple % | All % |
| Continence                   | 2           | —         | 40          | 20    |
| (controlled continence)      | (28)        | (—)       | (8)         | (10)  |
| Mobility                     | 51          | 2         | 50          | 37    |
| Behaviour                    | 6           | 38        | 48          | 36    |
| Speech                       | 2           | 52        | 76          | 53    |
| Personal care                | 20          | 13        | 72          | 44    |
| Education                    | —           | 67        | 88          | 62    |
| Number of young adults (100%) | 65          | 82        | 144         | 291   |

*a percentages sum to more than 100 because of multiple disabilities.

Table 1 shows the incidence of disabilities rated as moderate or severe. Many young people suffered from multiple disabilities: 71 per cent (206) suffered from three or more disabilities rated as mild or above, and only 15 per cent (44) had no moderate or severe disability.

Current medical care

Almost half (140) the young adults were under the care of a doctor, other than their GP, at the time of the survey. The majority of these were seeing an orthopaedic specialist (24 per cent) or a paediatrician (16 per cent). A wide range of other specialists was being seen including psychiatrists (15), neurologists (14), ophthalmologists (10), urologists (8), ENT specialists (7), and cardiac specialists (6). In addition, 13 young people were regularly seeing a doctor at school (21 per cent of those still at school); three saw a doctor at their adult training centre or college of further education.

Over a quarter (37) of the young people seeing a doctor other than their GP were seeing more than one on a regular basis. However, in only half of these cases (19) were carers able to identify someone who took overall responsibility for their son's or daughter's medical care.

Changes in the location of medical care

Since reaching the age of sixteen, almost a third (43 out of 140) of the young adults still seeing a doctor or consultant had experienced a change in the place where they usually went for consultation. This could involve a change of hospital, clinic, or department within a hospital. In over half these cases (23) the change had come about when the young person became too old for paediatric care or a children's hospital and had been transferred to an adult clinic or hospital. However, this change of hospital or clinic did not always imply a change of doctor: three carers mentioned that the young adult was seen by the same doctor as before.

The majority of carers (23) whose sons or daughters had changed hospital or clinic felt that the new arrangements for the young person's medical care were about the same as they had been before the change, or better (7 cases). However, 10 carers felt that the current arrangements represented a deterioration in care. The major complaint was that the new doctors appeared to know much less than their predecessors about the young people. For three young adults the transfer from one consultant (paediatrician), who oversaw all aspects of their health, to specialists, whose interests were in specific medical problems, caused anxiety and may have created gaps in their care:

'When D was at the children's hospital she had one doctor . . . who knew everything about her and how to deal with her, now she has two doctors it's confusing.' (Spina bifida)

'She has not seen anyone on the orthopaedic side—there has been a complete breakdown there.' (Cerebral palsy)

'He never gets thorough check-ups which I think he should get. I've had a lot of trouble to make them take notice of R's hernia which was only found out because I knew something was wrong, they would never have found it.' (Cerebral palsy)

Reduced accessibility to both advice and medical care and changed channels of communication disturbed some carers and in one case it was felt there could be serious consequences:

' . . . they're not keeping in personal contact and they'll be quite useless when he has to be admitted in status, in fact the hospital said they may not take him. At G. I used to phone them up and they'd say 'bring him in at once' but now it's very worrying because if they won't take him, it may be too late. He has so many drugs and at a strange place they won't be aware of it.' (Epidermal naevus syndrome)

Loss of medical care

The incidence of regular consultation had been higher in the past than it was at the time of the survey; more than 40 per cent (65 out of 151) who were not currently seeing a doctor, other than their GP, had done so at some time in the previous four years. Altogether, these 65 young people had been seeing 82 doctors on a regular basis in the recent past.

Past and present consultation rates with doctors other than their GP varied according to the nature of the young adults' impairment. The physically impaired were most likely to be under specialist care at the time of the survey whereas the mentally impaired were more likely not to
have had regular consultation at all in the recent past; of those who had, few had stopped seeing a specialist (Table 2). The multiply impaired were more likely to have had consultation with a paediatrician in the past (21 per cent compared with 5 per cent of the mentally impaired and 12 per cent of the physically impaired); they were also more likely to have lost this than other impairment groups. In general, young adults with multiple impairment were most likely, and those only with mental impairment least likely, to have lost medical consultation of whatever nature (Table 3).

Table 2. Consultation, past and present, by impairment.

| Impairment   | Physical % | Mental % | Multiple % | All % |
|--------------|------------|----------|------------|-------|
| Seeing doctor(s) now | 60 | 46 | 44 | 48 |
| Doctor(s) seen in past 4 years but not now | 28 | 11 | 26 | 22 |
| No doctor seen in past 4 years or now | 12 | 43 | 30 | 30 |
| Base (= 100%) | 65 | 82 | 144 | 291 |

Carers often mentioned the peace of mind that a regular, though not necessarily frequent, check-up would bring:

‘... it gives you peace of mind. I think they can see better how D. is developing.’ (Cerebral palsy)

‘... it would be nice to know there was someone.’ (Down’s syndrome)

‘Just for our own peace of mind to make sure everything is OK.’ (Mental retardation)

There was, too, the reassurance that someone was actually interested in the young person and was available for information or advice:

‘... I like to go and get their advice otherwise you feel as if you are left out on a limb.’ (Cerebral palsy)

‘I mean, if she has fits—they’d check the tablets with me and

Table 4. Reasons given for no longer seeing doctor.

| Reason                  | Paediatrician | School doctor | Orthopaedic specialist | Psychiatrist/ Specialty in mental handicap | Other specialist | Total |
|-------------------------|---------------|---------------|------------------------|-------------------------------------------|----------------|-------|
| Age-related             | 8             | 15            | 2                      | 4                                         | 3              | 32    |
| No longer necessary     | 6             | -             | 5                      | -                                         | 7              | 18    |
| Could do no more for young person | 2 | -            | 2                      | -                                         | 7              | 11    |
| Other                   | 1             | -             | 3                      | 3                                         | 6              | 13    |
| Number of doctors (8 cases missing) | 17 | 15 | 12 | 7 | 23 | 74 |
ask me about her fits. My GP just gives me repeat prescriptions. He doesn't see her. The specialist used to ask me if she was doing different things. I would like to feel an interest is still being taken.' (Microcephalus)

'If its only every six months, yes. I think they ought to see her . . . It's knowing in our minds there's someone interested.' (Epilepsy)

Acute medical or behavioural problems were implicated in only three cases where specialist care had been lost: one carer was experiencing difficulty managing her son’s allergies and asthma and felt that he was deteriorating; another young adult had started to soil himself; in a third case, the carer needed advice about her daughter’s sexual development.

The main conclusion from these findings is that where carers felt a need for ongoing medical consultation it was mainly for the guidance, support and oversight that had been lost, rather than for any specific intervention. Carers may have been advised to consult their GP when their sons or daughters had stopped seeing a specialist or the school doctor, but many clearly felt that their GP was not experienced enough to provide care and supervision:

'You're hardly getting any satisfaction. If you take him to your own doctor he has no time to spend with him. I think you should be able to see someone apart from your family GP.' (Mental retardation)

'My doctor is all right for coughs and colds, but anything more than that he should see a specialist'. (Down's syndrome)

'I think it would help iron out all the problems the GP is not specialised in.' (Cerebral palsy)

'[It would be] nice if they were given a medical. You do not hesitate to take them to the GP and it's so awkward waiting in the waiting room.' (Mental retardation)

There was little evidence that GPs took a major role in the young people’s medical care other than by responding to specific bouts of illness. Nor was there any evidence that GPs increased their oversight or took on the care and supervision provided by school doctors and paediatricians when these were lost after the patient had reached 16 years or left school. Nevertheless, three out of ten carers felt strongly that their GP could be more involved in the young adults’ health care.

Discussion

The transfer from child to adult health services can be problematic for young people with disabilities. The young person who has received paediatric care may not be referred to another specialist when he or she becomes too old to see the paediatrician. Young people who are referred may find that paediatric care is replaced by fragmentary services so that they have to visit different hospitals or consultants for each of their health problems and no specialist takes overall responsibility. Further, after leaving the school health service the young adult may lose regular medical supervision altogether if his or her GP is unable to assume responsibility for it.

This survey found no evidence of major shortcomings in the provision of medical care. However, a substantial minority of carers were anxious about the loss of supervision that had been provided in the past by a paediatrician or school doctor. Where medical care had been transferred from one doctor to another or to several there was some evidence that the changeover had not been smooth and that the new arrangements were less than satisfactory. These problems and anxieties might have been resolved in time but better communication between doctors, families and young people would have eased the transfer from paediatric care and the school health service, and might have avoided the difficulties reported by these carers.

The Royal College of Physicians recently recommended the appointment of senior medical officers to be responsible for organising and assessing the ongoing care of disabled school leavers in each District and the development of transfer procedures to ensure continuity of medical care after they become ineligible to see the paediatrician [14]. The College also stressed the need for better coordination between medical, employment, education, housing, and social services and, in another report, for a closer partnership between residential and community services [15]. Joint approaches are crucial if the care and support for young disabled people and their families are to be adequate during the transition period. The transfer from paediatric care to adult health services coincides with the transition from school to further education, employment or some alternative to work. It also coincides with other transitions including the change in status from dependent child to adult claimant of disability benefits. There is too the normal expectation of leaving home either temporarily as a student or permanently on finding a job, getting married or simply to lead a more independent life. In addition, there are all the usual physical, social and emotional stresses of adolescence which may be accentuated by disableness.

The implication is that medical care and supervision of young disabled adults will often be associated with several needs each of which may not be satisfactorily met by health service and other professionals working separately. At present, Community Mental Handicap Teams and District Handicap Teams provide multidisciplinary services in most areas but they are not well-geared to meeting the needs of young disabled adults, especially the severely physically impaired. One possibility would be their replacement by Handicapped Child Teams and Handicapped Adult Teams where the latter would have, as one of their functions, responsibility for all young disabled people [9].

Another possibility for ensuring continuity of care would be to develop a support service specifically for disabled school leavers. A model for such a development is provided by the Newcastle upon Tyne young adult clinic which offers a regional follow-up service for the physically impaired school leaver [16,17]. Over 320 people aged between 17 and 35 years have attended the clinic since 1979. Many young people attending paediatric services transfer to the clinic after reaching 16 and there are referrals from special schools, from medical
personnel and other professionals and, significantly, from the young people themselves. Problems handled include aids and appliances, mobility, medical complaints, housing, cash benefits, adaptations, communication, incontinence, leisure, employment, and sexual and genetic counselling. The clinic is staffed by an orthopaedic surgeon, a physiotherapist, an occupational therapist, and an information or welfare rights officer and formerly included a disablement resettlement officer and social worker. There is close liaison with local authority and health departments and GPs are sent copies of any notes when their patients attend. The clinic meets once a fortnight in a purpose-built centre for the disabled where daily living skills can be practised. This building, which is away from a hospital setting, accommodates an aid centre, an information and advisory service, a communication aid centre, and a continence advisory service, all of which are available if required by those attending the clinic. On alternate weeks the clinic meets in a community physiotherapy unit where an orthotist is available for splintage and appliances.

Conclusion

Young people with disabilities are particularly dependent for the quality of their adult life on the services provided for them. The findings of this study point to a failure to ensure continuity of care and practical support during the transition from school to adult life. As a consequence, services to promote their social integration and personal autonomy, and to help their carers, may often be lacking. There is an urgent need to develop a multidisciplinary follow-up and support service at District level to meet a wide range of needs in a way that young people themselves and their families find acceptable.

References

1. Thomas, E. and Ferguson, T. (1963) The handicapped school leaver. London: British Council for Rehabilitation of the Disabled.
2. Court Report (1976) Fit for the Future – The Report of the Committee on Child Health Services. Cmdn. 6684. London: HMSO.
3. Tripp, J. H. (1984) Unmet needs of handicapped young adults. Liverpool: Children’s Research Fund.
4. Anderson, E. M. and Clarke, L. (1982) Disability in adolescence. London: Methuen.
5. Castree, B. J. and Walker, J. H. (1981) British Medical Journal, 283, 1040.
6. Enticknap, B. (1983). Health Visitor, 56, 210.
7. Holland, M. B. and Gilbertson, M. P. (1983) Hospital services for young adults with spina bifida and hydrocephalus. London: Association for Spina Bifida and Hydrocephalus.
8. Paediatric Research Unit (1985) The needs of handicapped young adults. Exeter: Royal Devon and Exeter Hospital.
9. Thomas, A., Bax, M., Coombes, K., Goldson, E., Smyth, D. and Whitmore, K. (1985) Developmental Medicine and Child Neurology, 27 Supplement No. 50.

10. Bradshaw, J. (1980) The Family Fund. London: Routledge and Kegan Paul.
11. Bradshaw, J. and Lawton, D. (1985) Developmental Medicine and Child Neurology, 27, 25.
12. Hirst, M. A. (1983) Child. Care, Health and Development, 9, 273.
13. Hirst, M. A. (1984) Moving on: Transfer of young people with disabilities to adult services. York: Social Policy Research Unit, University of York.
14. Report of the Royal College of Physicians (1986) Physical disability in 1986 and beyond. Journal of the Royal College of Physicians of London, 20, 5.
15. Report of the Royal College of Physicians (1986) The young disabled adult. London: Royal College of Physicians.
16. Robson, B. J. (1980) Setting up a clinic for handicapped school leavers in Newcastle. Newcastle upon Tyne: Department of Orthopaedics, Freeman Hospital.
17. Robson, B. J. (1982) Report on the Newcastle Young Adult Clinic for the Disabled. Newcastle upon Tyne: Department of Orthopaedics, Freeman Hospital.