Transition from school to adult life for physically disabled young people

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Abstract

The transition process for young physically disabled people (n = 87) was studied in three districts to determine how it varied between schools, and how it was perceived by the disabled and their carers. The experiences of the young people were compared with guidelines for good practice based on relevant legislation. Results showed that young disabled people experienced a poor handover to adult services if they had no "statement of special educational need" or if they went to further education college. Young people with cerebral palsy or complex multiple problems fared less well than those with spina bifida or juvenile chronic arthritis. There are several deficiencies in the legislation. Physically disabled young people should receive a transition review regardless of whether they have a "statement". The range of severity and type of disorders among the young physically disabled argues for a range of services—the category is too broad to be useful for research, service planning, and provision.

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When disabled young people come to the end of their school years, and leave the domain of paediatric services, the quality of their medical care declines. A study in 1985 of 108 young physically disabled people described a high level of unidentified or untreated medical and psychological problems, as well as many social and financial worries.¹ Recently, these findings were replicated in a more detailed study in Liverpool.² However, there is little in the medical literature about the process of transition from paediatrics to adult services, the relevance of varying type and severity of disability, or the impact of legislation.

The 1981 Education Act dealt with the education of children with special needs. The 1993 Education Act, now consolidated into the 1996 Act, updated this legislation and a code of practice, issued by the Secretary of State as part of the implementation process, sets out how the legislation should be put into effect.³ The code describes a coordinated process involving the Local Educational Authority (LEA), the NHS, and the Social Services Department (SSD), and stresses the importance of multi-agency planning for transition to adult services. Table 1 summarises the provisions of the code of practice relevant to transition; note that it draws on legislation that was enacted, and should have been implemented, before 1994.⁴

Table 1 Relevant legislation, requirements, and weaknesses

Relevant legislation	Requirements	Weaknesses identified
The 1993 Education Act requires the Secretary of State to issue a Code of Practice giving practical guidance to LEAs	All those to whom the Code applies have a statutory duty to have regard to it	
Sections 321 and 323 of the Education Act 1996 (assessments): section 324 (1) (statements)—formerly sections 165, 167, and 168 of the Education Act 1993	LEAs must identify and make a statutory assessment of those children aged up to 19 who have special educational needs and who may need a statement. They must arrange and attend the first annual review, known as the transitional review, of a statement after the child's 14th birthday	Children without a statement are not covered by this legislation
Section 6: 44 of the Code of Practice states that the LEA should convene the first annual review of the statement after the young person's 14th birthday.	They must invite the child's parents, teaching staff members, social services, careers service, and anyone else considered appropriate (including health service)	
The Chronically Sick and Disabled Persons Act 1978 and the Disabled Persons Act 1986, sections 5 and 6	The LEA should seek information from SSDs as to whether a child with a statement is disabled and may require services from the local authority when leaving school. They must also inform SSD (if it is agreed that the child in question is disabled) between eight and 12 months before the expected school leaving date. The SSD must give an opinion as to whether each child with a statement at 14 plus is, or is not, disabled (based on the definitions in the 1948 National Assistance Act) or In Need (section 17 Children Act 1989)	Young people who remain in full time education after the age of 19 years and 8 months are not deemed to be leaving school
Children Act 1989, and the NHS and Community Care Act 1990	SSDs are required to arrange a multidisciplinary assessment and provide care plans for children and adults with significant special needs	
Further and Higher Education Act 1992	Further Education Funding Councils secure further education facilities and fund further education institutions. They must take into account the needs of students with learning difficulties and disabilities	There is no obligation on further education institutions to liaise with SSDs when the young person is due to leave their establishment

LEA, Local Educational Authority; SSD, Social Services Department.

Table 2 Sources of information used to compile the list of young disabled people

<i>Sheffield</i>
School leavers' assessment team (Social Services)
Special school for the physically disabled
Disablement Services Centre
Disability support team
Two young disabled teams
Community paediatric physiotherapy team
Wheelchair clinic
<i>Rotherham</i>
Paediatric Assessment Unit
Adult disability team
Child disability team
Monitor and developer of services for people with disabilities
Two special schools
<i>Chesterfield</i>
Child Development Centre*
Community physiotherapy service
Consultant rheumatologist
Wheelchair service
<i>Regional branches of voluntary organisations*</i>
Cerebral Palsy Association (affiliated to SCOPE)
Association for Spina Bifida and Hydrocephalus

*These groups obtained permission from each member before disclosing their names to the researchers.

Our paper examines the widespread assumption that improvements in the transition process should be reflected by improved outcomes for disabled people and their carers. Three hypotheses were formulated: (1) that the arrangements for handover to adult services would differ between individual schools and types of school; (2) that the experiences of the young disabled people would depend on the type, pattern, and severity of their disability, which in turn govern their school placement; (3) that the quality of the handover process itself would affect the perceptions of the people involved and the services that they subsequently received. The data are drawn from a study of the transition process for young physically disabled people, which is reported in detail elsewhere.⁵

Methods

Our study, which was approved by the relevant ethics committees, was carried out in three adjacent districts with a combined population of approximately one million people, between 1993 and 1996. The intention at the start of our study was to focus on physical disability rather than learning difficulties and to define physical disability in the same terms as in the mobility allowance legislation—that is, being: “unable or almost unable to walk”. Access was obtained to a range of record systems and registers (table 2) to compile a comprehensive list of such people who had left school and were between the ages of 16 and 25 years. Each name and address was checked with the Family Health Services Authority to ensure that, as far as possible, contact was not accidentally made with the family of a person who had died.

Each subject was then contacted by letter and asked if they would agree to be interviewed. Those who did not respond after two letters and had no phone number were visited and a further letter was delivered by hand. All responders who agreed were visited by one of the researchers.

For each subject, demographic details were recorded, and the Townsend scale⁶ was used to

classify the level of disability. A semi-structured interview was then undertaken, with the disabled person and/or carer eliciting information and opinions on the way in which the transfer from paediatric medical services and school to adult services was handled, and the young person's experiences of medical care and treatment since leaving school. Quantitative data were stored and analysed using SPSS. Each interview was tape recorded and transcribed.

Before the analysis of the transcripts, the relevant legislation was reviewed and the experiences of each individual were compared with the legal requirements (summarised in table 1). An ethnographic qualitative analysis of the interview material, based on grounded theory, was undertaken to define the main themes in the experiences and opinions reported. These were related to severity of disability, presence or absence of additional disability (in particular, learning disability), and type of school attended. The extent to which the legislative requirements were fulfilled was assessed in each case.

To define current service provision, interviews were undertaken with professionals including social services personnel responsible for disability care, community health care staff, general practitioners, head teachers of schools, and principals of colleges of further education.

Results

THE SAMPLE

A total of 519 names of individuals with possible physical disability was identified from 14 sources. One hundred and thirteen of these were excluded because further enquiry showed that they had predominantly or exclusively a learning disability rather than a physical disability; 103 could not be traced; 13 had died or were seriously ill; and 32 refused to participate after the first contact. Among the remaining 258 identified as probably having physical disability, it was impossible in many cases to assess the type or severity of disability from the available records and, therefore, we selected those patients whose records suggested that they might have a moderate to severe degree of physical disability, with or without associated learning disability. A total of 206 were considered suitable and 87 agreed to take part (56 boys, 31 girls). Pooled data from the three districts are presented except where a distinctive pattern of service or care delivery is described.

Although cerebral palsy and neural tube defects were the most frequent diagnoses, there were 40 with other disorders (table 3). Table 4 shows the relation between the severity of disability and the type of school attended by the young physically disabled people.

Because the data were often incomplete in the various registers it was not possible to compare the severity of disability or the social background in subjects interviewed with those not interviewed. However, compared with the ethnic composition of the population of the study districts, ethnic minorities are under-represented in the interview sample.

Table 3 Causes of disability

Condition	Total
Cerebral palsy	34
Spina bifida	13
Other*	40
Total	87

*Head injury, 4; Duchenne muscular dystrophy, 2; orthopaedic disorders, 3; stroke, 1; hypertensive encephalopathy, 1; juvenile chronic arthritis, 3; Rett's syndrome, 1; cerebral tumour, 1; other malignant disease, 2; cerebellar degeneration, 1; miscellaneous named syndromes, 11; diagnosis unspecified, 10.

Table 4 Severity of disability and school attended

School type	Severity of disability			Total
	Very severe or severe	Moderate	Slight or minimal	
Special school for people with physical disability	13	7	4	24
Special school for people with learning difficulty	22	3	5	30
Mainstream school	6	4	14	24
Integrated resource within mainstream school	3	6	0	9
Total	44	20	23	87

FIRST HYPOTHESIS: THERE IS A RELATION BETWEEN THE TYPE OF SCHOOL AND THE HANDOVER PROCESS

The data supported this hypothesis. Most of the young physically disabled people who had attended a school for people with learning difficulties had multiple impairments, and they all had a "statement of special educational need". In this group of young physically disabled people, the requirements of the 1986 Disabled Persons Act were generally fulfilled in that information was transferred between the LEA and the SSD as prescribed by the Act. Efforts had been made to ensure that the handover process was a shared responsibility between the three statutory agencies. In one of the three study districts there was a combined school leavers' assessment team including a paediatrician and representatives of the LEA and SSD; in another, young physically disabled people who also had major learning disabilities were supported by a specialist "nurse for transition", whose brief was to facilitate the transfer of care and information from the paediatric team to adult learning disability services. In the third district in our study, a social worker or careers officer interviewed the disabled person and then "represented" him or her at an all professional multidisciplinary planning meeting. Although these individuals appeared to have received good services, both the young physically disabled people and the carers of the profoundly disabled individuals often referred to "careers advice" and did not seem to regard the input they received as comprehensive transition planning.

In contrast, young physically disabled people attending a school for the physically disabled, a mainstream school, or an integrated unit usually had either normal intelligence or only a modest degree of learning disability. They received no multidisciplinary assessment. Three factors contributed to this. First, many of these young physically disabled people had no "statement". This was because a "statement" is issued only in response to educational needs; the severity of the physical disability is relevant only insofar as it affects the need for educational support. Thus, for young physically disabled people who did not need special help for learning, the school had no duty of notification to the SSD. Second, regardless of whether they had a "statement", many young physically disabled people left school and proceeded direct to a college at age 19. Thus, strictly speaking, they had not left fulltime education and, therefore, the formal notifica-

tion that the individual was about to leave the education system, as required by the 1986 Act, was never issued. As a result, the SSD did not know about the young physically disabled people or their needs when they returned to their home from college. The third factor was that the usual handover age from paediatric to adult services was 16 years, whereas the move from school to college for young physically disabled people is normally at age 19; thus, a lack of synchrony is built into the transition process.

SECOND HYPOTHESIS: THERE IS A RELATION BETWEEN THE HANDOVER PROCESS AND THE TYPE OR SEVERITY OF DISABILITY

The data also supported this hypothesis. Two groups of young physically disabled people who had a smooth and well defined transition from paediatric to adult services were those with juvenile chronic arthritis and those with spina bifida. The former were transferred from a paediatric to an adult rheumatology clinic but the same consultant attended both; the latter were transferred to a spinal injuries centre.

The transition experiences of individuals with cerebral palsy and with a range of other conditions were much more varied. None of the three districts studied had any adult medicine equivalent of the comprehensive service offered by a child development centre. Young people whose physical disability was mild or moderate were usually discharged back to their general practitioner when they reached the age of 16. Those young physically disabled people with more severe problems or who used orthoses were transferred to a neurologist and/or an orthotist. Only a minority knew about, or had access to, the services provided by a community physical disability or rehabilitation team. Such teams were only functioning in two of the five areas of one study district and not at all in the other districts, and they catered primarily for older clients who were victims of stroke, multiple sclerosis, or trauma.

Profoundly multiply disabled people with cerebral palsy received follow up at a combined clinic run by the consultant in rehabilitation medicine with a community paediatrician, which provided advice on medical issues, seating, and equipment, and linking with the support offered by the community learning disability team. This was valued, although there were varying views about ease of access to the learning disability team consultant and whether it was appropriate for someone with learning problems to receive their consultant support from a psychiatrist.

Inevitably, the severity of the disability affected the views expressed on the subject of continuity of care after handover, because those with profound multiple disability could not speak for themselves and it was necessary to rely on the views of the carers. Many carers of these individuals felt a clear sense of loss and betrayal when they were discharged from paediatric services; in contrast, those people who could speak for themselves were less concerned about the loss of continuity in medical care. A similar divergence of views was noted on the subject of physiotherapy services. A few

who went to residential college noted that local therapists had maintained contact during holidays.

THIRD HYPOTHESIS: THE QUALITY OF THE HANDOVER PROCESS AFFECTS THE PERCEPTIONS OF YOUNG PHYSICALLY DISABLED PEOPLE AND THEIR CARERS AND THE SERVICES THEY RECEIVE
In general, the hypothesis that a well structured handover process would result in more positive perceptions of the system by the carers and in better subsequent care was not confirmed, although there were exceptions, such as individuals with juvenile chronic arthritis. Unexpected transfers of medical care at short notice caused distress and anger. Although some carers had a positive memory of the care taken by the careers officer or school leavers' assessment team, and of the help given by the transition nurse, few had experienced a formal medical handover either then or subsequently. Some were disappointed that promised services had not materialised—even a well planned assessment did not guarantee that the recommendations would be honoured by service providers. This was usually because no effective community service was available where the individual lived, although in a few cases failure of communication was responsible.

PERCEPTIONS OF GENERAL PRACTITIONER CARE AFTER TRANSITION

The care offered by the general practitioner was valued for everyday medical problems, but neither the young physically disabled people nor their carers felt that the general practitioner would be the ideal person to consult for matters related directly to their disability.

Discussion

Studies of disability usually focus on people living in one district or area; therefore, generalisability of the findings is always open to question.^{7,8} The lack of a reliable register, the large number of disabled individuals who could not be contacted, and uncertainty about the direction of any bias that might result mean that any quantitative conclusions from our study must be tentative, although our design did allow us to compare models of care in three different districts.

The 1994 Code of Practice was implemented after the young physically disabled people in our study had left school, but most of the legislation quoted has been in place for some years and the problems identified are still relevant to the implementation of the code. The data indicate that, in spite of several reports on the issue, there are many unresolved problems in the transition process and subsequent care for young physically disabled people. The definition of learning disability, the registration of people with learning disability, and community teams catering for adults with learning disability are well established, so it was not surprising to find that the transition process also worked better for them than for those whose disability was predominantly or exclusively physical. The lack of any compara-

Key messages

- Young physically disabled people should receive a "14+ assessment" regardless of whether they have a "statement"
- A period away at college can result in loss of contact with social services
- The age of transfer to adult services should be flexible
- One service cannot cater for all: a range of adult services is needed
- Transition plans must reflect service availability
- The primary health care team must be involved throughout childhood and adolescence

ble definition or system for physical disability causes considerable difficulties for service delivery and for research.

In contrast to many other reports that have focused on cerebral palsy or spina bifida, we studied people with physical disability caused not only by neurological disorders but by a wide range of other conditions that do not conform to the usual concept of a physically disabled young person. This observation casts doubt on the justification of studying young people with physical disability as if they were a homogeneous group. A core group of individuals with—for example, athetoid cerebral palsy or spina bifida, correspond to the "image" of physical disability (and form an articulate lobby for better services), but people with physical disability differ so widely in their medical diagnosis, severity and pattern of disability, and associated impairments (notably intellectual deficits), and in their attitudes, morale, and service needs that it seems naïve to imagine that any one research initiative or new service provision could cater for such a disparate group of individuals.

The study showed that several issues must be addressed to fulfil the spirit of the 1994 Code of Practice. What can be done to improve the situation? First, the identification of all pupils who might benefit from a transition plan is essential. Most will already have a "statement" and should therefore be known to the LEA, but our study showed that there are many pupils with physical disability who do not have a "statement" because increasingly it is felt that their educational needs can be met without special provision. A recent review of transition recommended that: "It is helpful if, as a matter of good practice, the principles which apply to those young people who have a transition plan by virtue of their statement are also applied to those disabled people without statements."⁹

These young people may have little contact with their paediatric consultant if their physical state is stable, but they should all be known to the School Health Service. Ensuring that they are contacted and that their care and future needs are reviewed could be the responsibility of a school nurse or school doctor. We are currently investigating the first of these options.

Second, there must be a mechanism to ensure that when the LEA initiates the "14+ review process" for pupils with a "statement", the relevant paediatric services are notified and are involved with the development of the transition plan. Failure to prepare an appropriate plan might have adverse consequences for the young physically disabled person and could even be the subject of litigation.

Third, a range of possible services must be considered when planning the future care of young physically disabled people. Our study suggested that the handover of young people with juvenile chronic arthritis to an adult rheumatology clinic, and of those with spina bifida to a spinal injuries unit, might be successful, although few data are available on the long term outcome of such care. An alternative for the spina bifida group, where numbers justify the investment, is a dedicated service for adults.¹⁰

For people with profound multiple disability, the community team for learning disability is currently the usual choice, with access to additional services such as a seating clinic. This might not be the ideal solution, however, and some carers questioned whether a psychiatrist was the most appropriate specialist. In one of our study districts, a paediatrician has been seconded from the child development team to work alongside the consultant in rehabilitation medicine, providing some degree of continuity for the most complex problems and those with profound disability, although the question as to how many years this should continue is unresolved. The "nurse for transition" in another district was considered to be a valuable innovation, facilitating a smooth transfer for people with learning disability.

Medical care of people with cerebral palsy or with a range of other uncommon disorders still presents difficulties and the role of the primary care team is unclear.¹¹ We asked some general practitioners whether they might take responsibility for coordinating medical care for these people. These data are not reported in detail because they are the views of a small and unrepresentative sample; however, around half of the general practitioners contacted felt that they could and should handle this task, provided that there was a marked improvement in training, communication, information transfer, and access to specialist services that understood the needs of young physically disabled people. Paediatricians might make the young physically disabled people and carer more dependent on specialist services by providing an excellent service for their patients in child development centres, not only for the disability itself but also for minor intercurrent medical problems. This might undermine the relationship with the general practitioner, making it more difficult to take over the care when they leave the paediatric service.

Even if the general practitioner takes on the coordinating role, some young physically disabled people will need specialised services in adult life, in particular, for epilepsy, orthopaedic disorders, and gastrointestinal problems. In our study districts, several options are being

considered. Flexibility in the age at which transfer of care from paediatric to adult services occurs would be a vital part of all these options. The first option is the continuation of care by a consultant paediatrician beyond the usual handover age of 16 years; this would probably be ideal for conditions that severely limit life expectancy, such as Duchenne muscular dystrophy. The second is the continuity clinic run by a paediatrician in tandem with the consultant in rehabilitation medicine, as described above. This might be the best solution for people with severe physical or multiple disability. A third, long term aim, should be to improve training in the management of disability for all trainees in adult specialities, so that young physically disabled people receive the same quality of medical care from all specialists as do the able bodied.

There is now ample evidence that services for young physically disabled people are in need of improvement.¹² The considerable difficulties experienced in our study of identifying all the young physically disabled people in our districts suggest that current arrangements for registration and tracking of young physically disabled people are inadequate; better coordination between agencies could resolve this problem. Implementation of the 1994 Code of Practice would improve transition planning,¹³ but this will not in itself produce new or better services. The heterogeneous nature of physical disability means that there will be no single solution.¹⁴ Easier access to a single source of information about clinical and service issues for general practitioners, young physically disabled people, and their carers would help. The health of aging carers must not be neglected.¹⁵ Imaginative use of existing clinical expertise, and enhancement of existing resources such as rehabilitation clinics and community teams might be a more economical way of addressing the problem than creating a completely new rehabilitation service.¹⁶

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