

## **YOUNG PHYSICALLY DISABLED ADULTS: OUT OF SIGHT AND MIND? - (2) THE DIFFICULTIES FACED BY SEVERELY DISABLED PEOPLE LIVING AT HOME**

In an earlier paper we decribed the unsatisfactory situation of many severely 'physically disabled' adults who are resident in care homes. However the circumstances of those living in their own homes is often little better, and sometimes worse. This paper describes the difficulties faced by some 90 such individuals – identified during contacts with voluntary organisations that support people with neuromuscular disorders, Huntington's Disease, multiple sclerosis, acquired brain injury in children and epilepsy. For the first three conditions 'outreach workers' employed by the respective voluntary organisations visited people at home, as part of their work and usually on a number of occasions, to try to ensure that the disabled individuals and their families receive the services and opportunities needed for a satisfactory quality of life. For those with multiple sclerosis and epilepsy, individuals were interviewed during visits to therapeutic facilities provided by the respective voluntary organisations.

The most striking observation was the substantial difficulty being faced by most of the 90 individuals and their families. And although some of the difficulties were specific to one diagnostic group (particluarly for children with acquired brain injury), the great majority were common to all five groups.

### **The main problems identified**

Most of the problems identified may be classified as follows:

- social isolation - in the more extreme cases young adults being confined to their room and only receiving outside help (from th 'provider arm' of the social work department) for transfer from bed to a 'sling' in the morning, and back to bed again in the early evening.
- prolonged delays in receiving community care assessments (CCAs), support and other services. Some individuals had waited more than 12 months for a CCA – during which they unable to obtain necessary services, sometimeswith resultant and possibly permanent deterioration of physical, mental and social health
- prolonged delays and other difficulties in obtaining an appropriate wheelchair. This was an extremely common problem, and in several cases resulted in the individual being housebound for several months.
- lack of information about the progress of requests for CCAs, social work services,wheelchairs and other equipment
- services provided by the 'provider arm' of social work failing to meet the needs of almost all the young physically disabled clients contacted. Staff focused on doing things for clients rather than helping them to do things for themselves, and were unwilling to do even simple tasks which they regarded as outwith their remit (even putting a new supply of paper into a printer!). There were several reports of leaving a client on the floor because they were not allowed on their own to pick anyone up; and

others were had left immediately after preparing a meal in case the disabled person were to choke whilst eating. .

### **Why these difficulties exist**

*Poverty of resources.* It appears that the resources available for people who have a 'physical disability' are considerably less than those available for people with learning disability or mental health problems. This appears partly to be the result of less money accruing to the client group as a result of closure during the 1990s of longstay institutions, and partly because - with a higher political profile and perhaps more innovative and creative management - those working in the mental health field have been able to attract substantially more resources.

*Insufficient client- centredness.* Creative thinking, coupled with the availability of more adequate resources, has enabled those responsible for services for people with learning difficulty and mental health problems to develop a much more client-centred approach to the assessment of needs and to deliver a range of services and opportunities to meet these needs and to promote a fulfilling life. People with a physical disability on the other hand continue to be treated with paternalism, being 'assessed' to determine what they need, and with a focus on care and support rather than on enabling individuals to live to their potential.

*Inappropriate service provision.* For most people the main (and very often sole) source of help for those living at home is the provider subsidiary of the social work department ('DACs'). The primary focus of this service is the care of frail older people. The training, knowledge, skills and attitudes of the staff - and the whole ethos of the service - is entirely inappropriate for the needs of younger physically disabled people who wish to live an active and challenging life. Rather than doing things and caring for them for the disabled person, young people want to do things for themselves, experience a wide range of opportunities, and to take some risks. They need a wide range of experiences and opportunities from which to choose. A few fortunate people have been able to acquire the services of a personal assistant—either by means of a Direct Payment or from an agency on the social work department list of 'preferred providers'. These individuals receive services that are far more closely tailored to their needs than those have to rely on what is effectively direct service provision by social work.

It is curious that DACs reportedly will not accept training for its care staff from agencies that have particular expertise in supporting people with a severe disability- even for clients whose needs are very specialised, such as people with acquired brain injury, severe epilepsy or Huntington's Disease. Diagnosis is important: not knowing the underlying reason for 'unreasonable' behaviour has resulted in disabled people (and their family) being branded as lazy, dirty, difficult and even and offensive.

*Failure to monitor the progress of requests for help from social work.* This means that users are often entirely uncertain when contact will be made or when a service is likely to be accessible. And quite often when a contact is made users are uncertain of its nature - particularly whether or not a Community Care Assessment had taken place. However this situation does vary considerably between social work offices, even within the same local government area.

*Failure to identify serious problems.* Several of the 'outreach' workers immediately identified serious problems relating to a disabled person or to the household that health and social work professionals had either not themselves identified or had failed to address. These included at least one life-threatening situation, several instances where services had been withdrawn due to 'incompatibilities,' and others where users were living in entirely unsatisfactory conditions. It was almost as if the professionals involved were unable to detect or unwilling to deal with serious fundamental problems, preferring to focus on narrower issues.

*Fragmentation and loss of services after leaving school.* The young adults who were disabled whilst at school appeared in every case (apart from those with acquired brain injury) to have received a satisfactory range of services. These services however usually fall apart after leaving school, and regression in physical, mental and social wellbeing was remarked upon in many instances. One worker reported that it was not a case of 'falling through the net', but that "there is no net"..

### **Where do we go from here?**

In an earlier paper on younger physically disabled adults in care homes we described circumstances that cannot be allowed to persist. The same applies to most of those who live in their own homes. People with a learning disability and with mental health problems enjoy a far greater diversity and volume of services, and these are user-driven rather than imposed.

First, efforts are necessary to secure higher level of funding for this client group - to match those available for people with a mental health or learning disability. This will require 'physical disability' to be moved considerably further up the political agenda.

Second, there should be debate about the focus on medications which benefit only the very few, to the relative neglect of physical and other therapies and opportunities that may benefit many. If disabled people themselves were to prioritise medication, physiotherapy, the availability of personal assistance, and access to lifestyle opportunities and wheelchairs, medication may well not be top of their list. .

Third, 'physically disabled' people should be able to enjoy life to their full potential in the same way as people with a learning disability or mental health problem are helped to do. This means encouraging people to identify their own needs and helping them to make choices. A much more diverse range of opportunities for rehabilitation, meaningful activity and enjoyment is required, and a radical change of ethos from 'doing things for people' to encouraging and helping people to do things for themselves. *The need for younger disabled adults and elderly people are entirely different, and it is unacceptable for them to be supported in the same environment or by the same staff.*

Fourth is an urgent need to modernise social work services - to speed up and monitor the processes for dealing with enquiries, conducting 'assessments' and providing services. Users need to be kept informed, and the service should have mechanisms in place to audit its performance, including variations between different social work teams. New thinking is required - particularly in relation to self-assessment, self-management, encouraging the use of Direct Payments and the employment of personal assistants (eg Kent social services).

Although there is a Centre for Inclusive (Independent ) Living in Glasgow that exists to promote the interest of disabled people; however much of its funding comes from social work, and its own independence is therefore restricted at least to some extent.

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