After Transition: Health and Social Care Needs of Young Adults with Long-Term Neurological Conditions

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The Neurological Alliance (2003) has estimated that 10 million people in the UK are living with a neurological condition, over 8 million of whom manage their daily lives with short-term support. More than 1 million need some help with daily tasks and will be out of full-time employment, including most people with congenital conditions, acquired brain injury or illness, and those who have had a stroke or who live with motor neurone disease, multiple sclerosis, Parkinson’s disease or dementia. There are also about 350,000 people who require help for most of their daily activities.

The National Service Framework for Long-Term Conditions (Department of Health, 2005) lays down care standards that people with long-term neurological conditions should be able to expect from services. These include early recognition, specialist and community rehabilitation, vocational rehabilitation, equipment and accommodation, and personal care and support.

Transition – service needs and costs

Young people with long-term neurological conditions who are facing the transition from child to adult services often encounter particular challenges. Accessing the right support has been seen by many people as key in achieving independence and maximising opportunities to contribute to society and is an important policy concern.

There has been little work on the costs of services required to enable young adults with these conditions to live independently. PSSRU was asked by the DH to look at young adults with neurological conditions who have started to be supported by adult services. Links were made with the Department’s Research Initiative for Long Term Neurological Conditions (www.ltnc.org.uk) which started in 2007.

From the large number of neurological conditions relevant to this study, three were selected because of their relatively high prevalence, and because they encompass a range of impairments found among those with long-term conditions:

- Epilepsy is an intermittent condition, often stabilised with medication but where specialist services are needed during acute episodes or to respond to changing development or age-related needs.
- Cerebral palsy is an early onset condition that can have serious consequences for a child’s life that continue into adulthood.
- Acquired brain injury is a sudden onset disorder, often affecting people in this age group, where there is higher-than-average incidence of trauma from car accidents and sporting activities.

For each we addressed the same questions:

- What health and social care supports and services are currently used by young adults with these conditions?
- What are the costs of these health and social care supports?
- What unmet needs for health and social care services do they have?

Here we concentrate on cerebral palsy. Our full report will be available in 2008.
Cerebral palsy

Cerebral palsy (CP) covers a group of disorders that are permanent but not unchanging. Most people with CP (91%) have spastic cerebral palsy in which some muscles become stiff and weak, affecting their movement.

Our estimates show that at any one time CP will affect 9,400 young adults in the UK aged between 18 and 25 years. Around half of this group will have moderate to severe ambulatory disability and a similar proportion will have a moderate to severe manual disability. At least one in ten young adults with CP will have epilepsy, and about half will have moderate to severe intellectual disability.

Only five UK studies of young adults with CP were found that quantified health and social care needs or reported the costs of support. A common finding was that, compared to children, fewer young adults were using support services, and – where services were still used – it was at a lower intensity than before.

Only about 7% of young adults with CP are living in a staffed care setting; the great majority live with their parents. Around half of these young adults will be attending further education establishments, but one in six is not involved in constructive activity during the day and may have poorer quality of life as a result.

GP's and out-patient clinics are the most commonly used health care services. Although about a quarter of the young adults will be using physiotherapy, there appears to be considerable under-provision of this service. These young adults also want better access to counselling, orthopaedic and neurology services, and occupational therapy.

Just one in five young adults with CP is in contact with a social worker, yet research shows that this contact is a key resource for getting access to respite care. Contact with social services is similarly a pre-requisite for grants to adapt homes, referrals to housing departments, supported living grants and direct payments. We found no information on the levels of personal support required by young adults with CP yet such support is crucial in helping them achieve independent lives.

Costs of health and social care for a typical person with CP are £7,900 per annum (2005 prices), although this excludes the costs of transport help, aids and equipment, or formal (paid) personal assistance at home or in education. Our estimate for personal assistance would almost double the costs to health and social care services, adding £6,600 per person per year. There is likely to be a steep gradient linking costs to disability level.

Addressing unmet needs for community-based therapy would add another £800 per year to the costs of the 'typical' person with CP. For those currently unoccupied during the day, attendance at day activities (£1,730) or further education (£1,440) would increase costs again.

The total health and social care costs for supporting young adults with CP in the UK are estimated at £74.3 million or £136.6 million if the costs for formal (paid) personal assistance are included.

References