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

# PSSRU

## RESEARCH SUMMARY

48

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### TRANSITION – SERVICE NEEDS AND COSTS

The Neurological Alliance (2003) has estimated that 10 million people in the UK are living with a neurological condition, over 8 million of whom require short term support to manage their daily lives. Over 1 million need some help with daily tasks and will be out of full-time employment, and about 350,000 require help for most daily activities.

Young adults with long-term neurological conditions who are facing the transition from child to adult services often encounter particular challenges. Accessing the right support is key to achieving independence and maximising opportunities to contribute to society, and is an important policy concern.

There has been little work on the use or costs of health and social care services required to enable young adults with these conditions to live independently. PSSRU was asked by the Department of Health to look at young adults aged 18–25 years with neurological conditions who have started to be supported by adult services. Links were made with the Department's *Long-term Neurological Conditions Research Initiative* which commenced in 2007 ([www.ltnic.org.uk/research.htm](http://www.ltnic.org.uk/research.htm)).

From the large number of neurological conditions relevant to this study, three were selected. Each belonged to a different category identified in the National Service Framework for Long-Term Conditions: epilepsy is an example of an *intermittent* condition; cerebral palsy is an *early onset* condition; and acquired brain injury is a *sudden onset* disorder (DH, 2005).

For each condition we addressed the same questions:

- What health and social care services are currently used by young adults?
- What are the costs of their health and social care support?
- What are the wider impacts and unmet needs for health and social care services?

We used three approaches to identify information. We searched relevant policy and research literature for information on prevalence, use of health and social care services and other supports, and costs. Second, we searched through relevant datasets and their accompanying reports for similar data, and carried out some new analysis. Third, we consulted with experts in academia, specialist neurosurgical centres and rehabilitation units, professional associations, and in condition-specific organisations in the voluntary sector. The lack of directly relevant information meant that we have built up the best picture possible from a patchwork of sources. New primary data collection was not possible as the research described here was carried out over just a few months.

### EPILEPSY

Epilepsy is an *intermittent* condition, characterised by unprovoked seizures. It is often stabilised with medication but specialist services are needed during acute episodes or to respond to changing development or age-related needs. Epilepsy is one of the more common neurological conditions, affecting around 42,000 young adults aged between 18 and 25 years in the UK at any one time. Over 60% of this group will be seizure-free through the use of anti-epileptic medication. Between a fifth and a quarter will have intellectual disabilities (ID) alongside their epilepsy and this group are more likely to have continuing seizures than those without ID. About a third will have co-existing mental health problems, commonly depression, panic disorder, or anxiety.

Most young adults with epilepsy live independently or with their parents. Those who are seizure-free and who have no additional health problems have low health and social care needs. Just over half of those aged between 18 and 25 years are employed. In contrast, 11,500 young adults with epilepsy in

the UK live in staffed accommodation. One in four of these people live in wards, hostels or group homes run by the NHS; the others generally live in local authority or independent sector residential homes. Most have additional intellectual disabilities. The total cost of this specialised accommodation is £715.3 million, 40% of which is borne by the NHS (2005 prices).

Other services which provide important support for people with epilepsy are in- and out-patient hospital services, and services from mental health professionals, GPs, nurses, respite care facilities, social workers, and care assistants. The total cost of these community-based services is £8.9million, of which hospital services account for 62% and social care services a further 28%. However, as most studies and routine data collections report only health care utilisation, the costs associated with social care services may well be an under-estimate.

Our estimate of the average cost of health and social care support is £17,200 per young adult per year (2005 prices).

### CEREBRAL PALSY

Cerebral palsy (CP) is an *early onset* condition that can have serious consequences for children that continue into adulthood. CP covers a group of disorders that are permanent but not unchanging and most people with CP (91%) have *spastic cerebral palsy* in which some muscles become stiff and weak, affecting their movement.

At any one time there will be about 9,400 young adults in the UK who are aged between 18 and 25 years and have CP. Around half of this group will have a 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. There is likely to be a steep gradient linking costs and disability level.

Only about 7% of young adults with CP live in staffed care settings – the great majority live with their parents. Around half of the young adults with CP will be attending further education establishments. GPs and out-patient clinics are the most commonly used health care services.

Support costs for a typical young adult with CP are £7,900 per annum (2005 prices), although this excludes costs for transport help, medication, aids and equipment, or formal personal carers 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.

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

## ACQUIRED BRAIN INJURY

Acquired Brain Injury (ABI) is a *sudden onset* disorder. Road traffic accidents, assaults, fights and falls are common causes among young adults aged 18–25 years old. ABI prevalence rates are difficult to find because of the many causes so our incidence-based approach starts with the number of young adults injured and attending hospital and then tracks their care pathways over a notional 12-month period. We could not model the extent to which people ‘move on’ to less dependent placements over a longer period.

Young adults aged 18–25 comprise 10.4% of the population and this figure has been used to estimate the incidence of ABI in 18–25 year olds as a proportion of the overall A&E attendance rate for ABI (n=15,600 young adults). This approach may underestimate the number of young adults as ABI incidence rates peak during young adulthood and diagnosis of ABI may be poorly recorded at A&E or on the inpatient ward.

Most incidents of ABI require little more than a visit to the A&E department or a short stay for observation at the local hospital, although one in five may continue to have residual symptoms six months later, such as dizziness or poor concentration. The total annual costs for this group are £23.8 million or around £240 per young adult.

Health and social care costs are much higher for those people who have ABI-related disability. This will be around 1600 young adults, about 10% of those seen at hospital, costing health and social care budgets at least £47.2 million each year. We have distinguished three groups by their likely care location after hospital treatment and rehabilitation.

We estimate there will be around 350 young adults who are likely to return to their own homes. Many will have stayed in hospital for a month or more and about a third will have had a prolonged period of rehabilitation. The average health and social care costs over the 12-month period are £16,970 per person. A further 940 young adults will continue to require support either in their own homes or in low-support congregate settings, of whom about one in five will have stayed at a residential rehabilitation unit; average annual costs will be £32,900 per person. Finally there will be around 310 young adults who are severely disabled as a result of their ABI. About half of this group will have stayed in a rehabilitation unit but all are resident in high dependency placements at an average cost per person of £33,900 over the 12-month period.

## CONCLUDING COMMENTS

The overwhelming picture that emerges from these three detailed studies of young adults with neurological conditions is that

- there is widespread under-recognition of needs and poor support during the transition to adult services;
- discontinuities in service contact are common;
- social care support is frequently reported as low;
- many young adults remain heavily dependent on their parents; and
- opportunities for independence are severely restricted.

Shortages of specialist services and staff and specialist training for generic staff are partly to blame. In particular we found numerous reports of the lack of community-based therapy services and of low specialist knowledge for young adults who also have intellectual disabilities or mental health/behavioural problems. Two other areas of unmet need were striking; day time activities and information.

The data suggest that a quarter of young adults with epilepsy are permanently unable to work and one in five young adults with CP stay at home

with no formal day time activity. Many young adults with epilepsy or CP had entered further education courses but the high unemployment rates suggest that attendance does not always improve access to work. Community-based day activities for young adults with ABI also appear to be in short supply. Of course, these low engagement figures may just reflect poor levels of information but while the absence of meaningful day activities will suit many young adults, for others it may restrict skill acquisition and lead to a poorer quality of life.

Finally, the lack of information did not only affect this research. Young adults and their carers were concerned about the lack of information about the condition, its implications for other areas of the young adults’ lives, and the services that were available. For agencies poor information about the numbers of young adults in their area and their health and social care needs leads to difficulties in planning, commissioning and providing appropriate levels of support.

## REFERENCES

- DH (2005) *The National Service Framework for Long-Term Conditions*, Department of Health, London.
- Neurological Alliance (2003) *Neuro Numbers; a Brief Review of the Numbers of People in the UK with a Neurological Condition*, Neurological Alliance, London.

### Further information

A version of this summary, with more information on our findings concerning cerebral palsy, appeared in PSSRU Bulletin 17, December 2007, and can be downloaded from the PSSRU website: [www.pssru.ac.uk/pdf/b17/b17\\_youngadults.pdf](http://www.pssru.ac.uk/pdf/b17/b17_youngadults.pdf) (2 pages, 84KB pdf file).

Related research is reported on the website of the Long-Term Neurological Conditions Research Initiative: [www.ltnc.org.uk/research.htm](http://www.ltnc.org.uk/research.htm)

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