

Response of the Royal College of Paediatrics and Child Health

Comprehensive Spending Review 2007

You will have already received a detailed response from the British Association of Childhood Disability (BACD). This is our RCPCH-affiliated specialty group for neurodisability, which has multidisciplinary and multi-agency membership. However, we are grateful for the opportunity to submit further evidence since, as discussed, it was difficult to get full responses from our members over the summer, but we are continuing to get further information coming through now.

It is perhaps important to note that although our members do not necessarily have access to detailed information about the full economic costing of disability services, we are able to get more comprehensive information through multi-professional channels – hence the primary response being from BACD. However, if there are more targeted areas that you would like information on as your analysis proceeds, we would be very happy to try and answer further specific questions.

These comments should be taken in conjunction with the points raised through BACD, but the issues we particularly wished to highlight are as follows:

Changing profile of disabled children

- The submission from BACD has already noted that in the last 20 years the population of children and young adults with profound and multiple disabilities has increased. Data from Australia and the UK demonstrate increased survival and increased complexity of need. This huge increase in need, demand and expectation has not led to a parallel increase in service provision in health, education or social services.
- In terms of specific subgroups, as has been widely reported, there are greater numbers of young people being diagnosed with Autistic Spectrum Disorders (ASD). The National Survey of Mental Health of Children and Young People 2004 put the prevalence at 0.9% (1.4% of boys), and figures of 1% overall are now reported¹. Three quarters do not have learning disability, but their service needs are overlooked.
- You will be aware that the most comprehensive data on outcome of premature infants comes from the EPICure study which looked at outcomes for a large cohort comprising all births in 1995 in the UK and Republic of Ireland between 20-25 weeks gestation. Broadly this demonstrated that 50% of survivors had some degree of disability. Of these, half had relatively mild impairments and half had moderate to severe disability. However this data is, of course, now quite out of date, and we are embarked on EPICure 2.
- With regard to technology dependent children at home, in 2000 Glendinning et al² estimated the numbers to average about 500 per region. The authors of

¹ Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D., Charman, T. Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP) (2006) *Lancet* **368**: 210-215.

² Glendinning, C., Kirk, S., Guiffrida, A., Lawton, D. Technology-dependent children in the community: definitions, numbers and costs (2000) *Child: Care, Health and Development* **27(4)**: 321-334.

this paper noted that a low-prevalence high-cost condition such as this is hard for individual PCT and local social service departments to cater for, with costs per child ranging from £25,000 to as high as £150,000. Since that study, figures have clearly risen for all the reasons outlined above. It is also important to bear in mind the rising prevalence which comes from cumulative numbers of such children continuing to do well in home settings. For example, in North Shields referral of children with combinations of nasogastric feeding or gastrostomy plus oxygen dependence or a tracheostomy have plateaued at about 3 per year between 2000 to 2006 – but the cumulative number on the local caseload is continuing to climb.

Initial assessment and early intervention

- The waiting time targets are not helping families of disabled children. The times relate currently to medical appointments only and optimal care for these families involves seeing more than one kind of professional at a time e.g. paediatrician, speech and language therapist and psychologist for autism assessments. For example, a recent audit in Islington in London demonstrated that the average total time spent in assessing children with autism over an 8-month period was 87 hours per child for those under 5 and 106 hours for those over 5 (including time of paediatrician, speech therapist, psychologist, occupational therapist, social worker, advisory teacher, key worker, family counsellor, and administrator)
- Early intervention in ASD leading to improved outcome in function is critical. Delays in access to diagnostic services will have economic implications for educational support and later adult function.
- Provision of early advice around autism and ADHD may well decrease secondary behaviour problems and advice on sleep could significantly reduce stress on many families.

Ongoing service provision

- Much progress has been made in improving coordination of services and in innovative use of staff e.g. specialist nurses in neurology, epilepsy and ADHD. This is cost effective and delivers good outcomes. Group work can also be very effective for some families e.g. with autism. However, the ever increasing demands threaten to undermine these improvements by spreading services too thinly.
- We are particularly aware of problems in accessing therapy services because posts are being frozen, cut or not created at all.

Older children and transition

- Key workers are increasingly used, especially for young children with complex disabilities, but this needs to be expanded to cover older children and those with less profound but still complex needs e.g. ASD and ADHD.
- The needs of high functioning individuals are frequently neglected, and this is a group which struggles in the absence of appropriate expert support and advice in mainstream settings. Pat Howlin has demonstrated that the likelihood of adults with ASD, even with high functioning autism of Aspergers being fully socially and economically independent is limited, and that support

programmes are essential in order to improve these outcomes³. Those with Asperger syndrome have a higher psychiatric morbidity and have a significant suicide risk, further necessitating appropriate and skilled mental health input.

- There are problems for the majority of children with disability at transition, and there is often a lack of appropriate services to cater for their needs. This point will doubtless have been raised by many other agencies. This is particularly the case for those with severe physical and cognitive impairment (i.e. the PMLD population). In contrast to children with other long term conditions such as diabetes or renal impairment, there is frequently no adult counterpart to the paediatrician to take over the co-ordinated medical care of these individuals, and once outside the school environment, therapy services are also often severely limited.
- Adolescents with severe learning disability and either physical healthcare needs or challenging behaviour are particularly poorly served. Inpatient services are rarely equipped to cater for their needs and those with challenging behaviour often end up being managed in private healthcare facilities because of a lack of NHS alternatives.

Broader paediatric service issues

- Finally we would like to draw attention to the knock-on effect of the current pressures on acute paediatric services for those with disability and / or needing planned or long term care. We have raised this problem with both the DH and with Ministers.
- We are currently seeing an increased dependence on acute paediatric services, with an 18 – 20% rise in the numbers of children presenting to A & E departments over the last few years. We are also seeing increases in the numbers admitted, and this despite the current policy drive to deliver more care outside hospital. We believe these trends are partly due to the changes in the GP contract and the different arrangements for out-of-hours services, and partly due to changed parental expectations.
- Because of a number of other additional pressures, including the European Working Time Directive, and the current changes to medical training (Modernising Medical Careers), our workforce is further stretched. Given its limited capacity, an increased demand for acute services taps the same resource that might otherwise be diverted into planned care.
- We are also concerned about inadequate investment in consultant expansion. We currently have about 2800 consultants, along with a sizeable proportion of staff and associate specialist grade doctors who number about 1300 and are an important part of our workforce. Consultant numbers were increasing by 7% per year between 2001 and 2003 but that growth has now slowed to 5% between 2003 and 2005 which we think is partly due to financial constraints currently facing Trusts.
- Our conclusion is that we cannot continue to maintain 24-7 acute services on the number of sites on which paediatric services are currently being delivered. The relevance of this for those with disabilities is that unless there is reconfiguration of hospital services alongside more proactive multi-

³ Howlin P, Goode, S Hutton, J, Rutter, M. (2004). Adult outcomes for children with autism. *Journal of Child Psychology and Psychiatry*, **45 (2)**: 212 – 229.

disciplinary team development, and appropriate investment in consultant expansion, the limited paediatric workforce will be largely absorbed delivering acute care, at cost to those with longer term conditions.

We hope this information is helpful, but would be very happy to answer any specific queries and / or provide input into further workstreams.