



editorial

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Services for children with learning disabilities

There is a large body of research showing that there is a much higher prevalence of psychiatric disorders in children and adolescents with learning disabilities than in those without (Dykens, 2000; Stromme & Diseth, 2000; Tonge & Einfield, 2000; Emerson, 2003; Whitaker & Read 2006; Department for Education and Skills & Department of Health, 2006). People with psychiatric disorders and learning disabilities have poorer educational qualifications, do less well in the labour market and have lower income than other people (Prime Minister's Strategy Group, 2005). Despite the clear need for mental health services for children with learning disabilities, they are not universally available and often under resourced within Child and Adolescent Mental Health Services (CAMHS).

Background

For at least 15 years the government has highlighted the need to improve health services for people with learning disabilities (Department of Health, 1992). Organisations such as the British Paediatric Association in 1994, the Mental Health Foundation in 1996 and its sister organisation the Foundation for People with Learning Disabilities in 2002, have peppered the national document landscape with texts calling attention to the mental health needs of children with learning disabilities. Policy documents such as the National Health Service (NHS) Plan (Department of Health, 2001), the National Service Framework for Children (Department for Education and Skills & Department of Health, 2004a) and its update on progress (Department for Education and Skills & Department of Health, 2006) and the Special Educational Needs Action programme (Department for Education and Skills, 2001) have all highlighted the need for comprehensive, accessible mental health services for this group of children. However, many of these children and their families still have no access to a comprehensive, needs-based service. Initiatives such as the recent 'do once and share' project (Connecting for Health, 2006) make sound recommendations about service development but there is difficulty in their implementation as no one agency, commissioning body or organisation takes responsibility.

No universal service

This vast documentation has not led to any satisfactory 'mainstreaming' of children with learning disabilities into policy initiatives (Russell, 2003) or into practical and accessible mental health services. Indeed, some CAMHS still provide limited or no services for children with moderate to severe learning disabilities (York & Lamb, 2005; Department for Education and Skills & Department of Health, 2006).

Despite the fact that children with learning disabilities are a group at risk, the standard of mental health services for them is often well below expectations, and it is often the case that children are not accepted because they fail to meet entry criteria (McCarthy & Boyd, 2002). General practitioners feel untrained and ill-equipped to deal with mental health problems presenting in people with learning disabilities (Mencap, 2004). Even where tier two and three specialist services are provided, the shortage of resources may lead to a policy focusing on treatment rather than prevention (Foundation for People with Learning Disabilities, 2002). Although the NHS tier four in-patient provision is essential when severe or complex illness cannot be contained in family or community services (Hepper & Rose, 2004), it is not co-ordinated and in some regions it is absent altogether, leaving private units (O'Herlihy et al, 2001) and secure social services accommodation (Allington-Smith, 2006) to plug the gaps. Furthermore, the impact on families is considerable (McIntyre et al, 2002) and this has its own health and economic price; transition into maturity raises many additional issues for the provision of services (Hepper & Garralda, 2004).

Despite numerous government documents issued for the past 15 years, there has been little appreciable impact on mental health services for children with learning disabilities. In June 2006, only 59% of primary care trusts commissioned mental health services for young people with learning disabilities (Department for Education and Skills & Department of Health, 2006). Bearing in mind that clear commissioning guidance was first given 9 years ago (Department of Health, 1998), and that the Human Rights Act 1998 and the Disability Discrimination Act 2005 are now in force, this lack of services seems extraordinary.



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Why are the resources so scant?

Responsibility for children with learning disabilities and mental health problems historically fell between developmental or community paediatrics, CAMHS, and all age services for people with learning disabilities (Berney, 2006). Standard 8 of the National Service Framework for Children clarifies this stating that local authorities, primary care trusts and CAMH services must work together to 'ensure that disabled children have equal access to CAMHS' (Department for Education and Skills & Department of Health, 2004b).

Ineffective resource use

Additional funding for CAMHS has been provided recently through the NHS Modernisation Fund and the CAMHS grant (Department of Health, 2004). The grant was paid to local authorities, to be spent in accordance with a joint strategy agreed with CAMHS. However, these CAMHS development monies have often not gone towards services for children with learning disabilities. They have been directed at other targets (e.g. establishing core services) or priority groups (e.g. looked-after children and young offenders). Recently cash-strapped trusts and strategic health authorities have been taking back some of the development monies, reducing their budgets for CAMHS. Resources are often provided only for short, fixed time periods. For example, the early support programme 'Every Child Matters' funded by the Department for Education and Skills (2003) was developed in conjunction with the Department of Health as a 3-year funded programme. This funding is shortly about to come to an end in most areas and joint partnership agreements are struggling to continue funding the service.

Ineffective commissioning

If it were true that local provision was tailored to the needs of client groups and local priorities, then commissioning would have been expected to come into play for this group a long time ago. There is no clear planning function that links government priorities with local service provision. Some commissioners have no local needs assessments to guide them; and commissioning, which can appear to be reactive rather than proactive, does not seem to be able to make the necessary changes. Additionally commissioners rarely transfer resources from one service to another since reducing resources to any service is usually unpopular and may be damaging. Thus new developments can only occur with new money. The debt of the NHS trusts has reduced their financial flexibility. Joint commissioning makes good sense but it is not yet delivering effective service.

Further developments

The Public Service Agreement targets introduced three proxy indicators for improvement in CAMH services, one of which was that a full range of CAMHS be available and

accessible for children and young people with learning disabilities (HM Government, 2007a). An update in April 2007 (Department of Health, 2007) reported that only 41% of CAMHS had met this target by March 2005 but by December 2006 this figure had risen to 88%.

Considering the fact that many CAMHS were asked to meet this target without additional resources, there is a strong cause for concern in areas where CAMHS budgets are tight. The Healthcare Commission monitoring this process seems to have ignored the fact that many CAMHS, previously apparently without the skills to provide for this group of children, are now doing so at the request of commissioners, but without additional funding or training. This calls into question the whole commissioning process.

The government declared that 'disabled children should be considered both a local and a national priority' and suggested giving commissioners 'incentives' to focus on this group (HM Treasury & Department for Education and Skills, 2007) and recognised a 'need to do more'. A review (HM Treasury & Department for Education and Skills, 2007b) calling for evidence about the barriers to effective commissioning of services was carried out and it is likely to be a crucial piece of work on this subject. Properly resourced joint commissioning seems the obvious way forward.

In July 2007 the Prime Minister commissioned a major new review of the NHS (Hansard, 2007). Three of the four key areas identified are directly pertinent to children and young people with learning disabilities, namely:

- 'Improving patient care, including high-quality, joined-up services and ensuring patients are treated with dignity'
- 'Delivering more accessible and more convenient care integrated across primary and secondary providers, reflecting best value for money'
- 'Establishing a vision for the NHS based more on patient control, choice and local accountability and services responsive to local communities.'

All of these will be useful reference points for ongoing reviews of services and commissioning processes.

What should a good service look like?

Children and young people with learning disabilities should have access to good mental health services and there is an ongoing debate about what a good service should look like. Three models have been discussed by various authors (Berney, 2000; Williams & Wright, 2003): a lifetime learning disability service, stand-alone learning disability specialist CAMHS services, and learning disability CAMHS services within a generic CAMHS team. The option of a lifetime service (historically more prevalent than currently) offers the least in terms of dedicated child trained specialists who are used to liaising with professionals from other child agencies and it does not satisfy Standard 8 of the National Service Framework. Specialist stand-alone 'supra district' CAMHS services



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(Berney et al, 2004) offer high levels of expertise but if they were the only available services would they be as readily accessible and affordable as generic CAMHS? Specialist provision, including in-patient services, could be a regional resource alongside local service provision, which is essential. The most likely model for such local services would be specialist tier three teams embedded within generic CAMHS teams (Green et al, 2001; Williams & Wright, 2003). This has the advantage of cross fertilisation of ideas including joint training and working, secondments and healthy career pathways. It prevents a team from becoming isolated but retains staff with more experience and training in the area. It also provides local services and equity of access.

Alongside the three options outlined above comes the issue of who should manage these services. The jury is still out on this as services are currently variously managed by primary care trusts, community, childcare or care trusts and mental health trusts, and this is changing all the time with current trust reorganisation. These present opportunities for better co-operation and patient transition between organisations (depending on alignments). For example, being in a care trust may make co-operation with social workers much easier, while being in a trust that includes adult mental health or learning disability services might improve transitions between child and adult services. The team needs to be multidisciplinary (Allington-Smith, 2006). High levels of planning, co-working and co-operation between agencies (social services, child health, education, voluntary agencies and CAMHS) is essential both for community services (Beresford & Sloper, 2004) and for in-patient services (Gowers & Cotgrove, 2003).

Trusts should provide a full range of services similar to generic CAMHS including assessment, a diagnosis, a comprehensive array of interventions at all tiers and consultation services. Specialist knowledge will be necessary for physical comorbidities, epilepsy, autistic spectrum disorders, neurodegenerative and metabolic disorders, and teams will need specialist skills in dealing with challenging behaviour and child protection (Williams & Wright, 2003).

Where studies have sought user opinions about the services, they often express a desire for key workers, access to multidisciplinary services and good quality, readily available information (Beresford & Sloper, 2004). High-quality family support, leisure facilities and substitute care are also priorities for families.

An editorial in 2 or 3 years' time may comment on what progress has been made in providing services for children with learning disabilities and mental health problems and their families. It will be a sad indictment of the government, commissioning processes and CAMHS professionals if the situation has not improved. This paper is a call for all these groups to continue to work together urgently to address the problem.

Declaration of interest

None.

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References

- ALLINGTON-SMITH, P. (2006) Mental health needs of children with learning disabilities. *Advances in Psychiatric Treatment*, **12**, 130–138.
- BERESFORD, B., CLARKE, S. & SLOPER, P. (2005) *Integrating Services for Disabled Children, Young People and Their Families in York: Consultation Project*. Social Policy Research Unit, University of York.
- BERNEY T (2000) *Psychiatric services In Developmental Disability and Behaviour* (eds C. Gillberg & G. O'Brien), pp. 159–170.
- BERNEY, T. (2006) The new developmental psychiatry. *Advances in Psychiatric Treatment*, **12**, 138–140.
- BERNEY, T. P., BOWMAN, F., BRETHERTON, K., et al (2004) Psychiatric services for children and adolescents with learning disabilities. *Royal College of Psychiatrists Council Report CR123*. Royal College of Psychiatrists.
- CONNECTING FOR HEALTH – DO ONCE AND SHARE (DOAS) PROJECT (2006): *CAMHS Learning Disabilities – Developing a National Care Pathway* (<http://www.camhs.org.uk/default.aspx?q=DOAS&C=8970>).
- DEPARTMENT FOR EDUCATION AND SKILLS (2001) *Special Educational Needs (SEN) Code of Practice*. Department for Education and Skills.
- DEPARTMENT FOR EDUCATION AND SKILLS (2003) *Every Child Matters*. TSO (The Stationery Office).
- DEPARTMENT FOR EDUCATION AND SKILLS & DEPARTMENT OF HEALTH (2004a) *National Service Framework for Children, Young People and Maternity Services*. Department of Health.
- DEPARTMENT FOR EDUCATION AND SKILLS & DEPARTMENT OF HEALTH (2004b) *National Service Framework for Children, Young People and Maternity Services. Standard 8. Disabled Children and Young People and Those with Complex Health Needs*. Department of Health.
- DEPARTMENT FOR EDUCATION AND SKILLS & DEPARTMENT OF HEALTH (2006) *Promoting the Mental Health and Psychological Well-being of Children and Young People: Report on the Implementation of Standard 9 of the National Service Framework for Children and Young People and Maternity Services*. Department of Health.
- DEPARTMENT OF HEALTH (1992) *Health Services for People with Learning Disabilities HSB(92)42*. Department of Health.
- DEPARTMENT OF HEALTH (2001) *From Vision to Reality*. Department of Health.
- DEPARTMENT OF HEALTH (2004) Child and Adolescent Mental Health Service (CAMHS) Grant Guidance 2005/06. Department of Health (http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Localauthoritiesocialservicesletters/DH_4071374).
- DEPARTMENT OF HEALTH (2007) Children, Families and Maternity E-Bulletin. Gateway reference 8075.
- LINDSEY, M. (1998) *Signposts for Success in Commissioning and Providing Health Services for People with Learning Disabilities*. Department of Health.
- DYKENS, E. M. (2000) Psychopathology in children with intellectual disability. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **41**, 407–417.
- EMERSON, E. (2003) Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. *Journal of Intellectual Disability Research*, **47**, 51–59.
- FOUNDATION FOR PEOPLE WITH LEARNING DISABILITIES (2002) *Count Us In: The report of the committee of inquiry into meeting the mental health needs of young people with learning disabilities*. Mental Health Foundation.
- GOWERS, S. G. & COTGROVE, A. J. (2003) The future of in-patient child and adolescent mental health services. *The British Journal of Psychiatry*, **183**, 479–480.
- GREEN, K., WILLIAMS, C., WRIGHT, B., et al (2001) Developing a child and adolescent mental health service for children with learning disabilities. *Psychiatric Bulletin*, **25**, 264–267.
- HANSARD (2007) Statement to the House of Commons by Rt Hon Alan Johnson MP, Secretary of State for Health, 4 July 2007, on the Darzi review of the NHS. Houses of Parliament.
- HEPPER, F. & GARRALDA, M. E. (2001) Psychiatric adjustment to leaving school in adolescents with intellectual disability. *Journal of Intellectual Disability Research*, **45**, 521–525.
- HEPPER, F. & ROSE, G. (2004) Use of an in-patient psychiatric service by learning disabled children. *British Journal of Learning Disabilities*, **32**, 119–122.



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- HM GOVERNMENT (2007a) PSA Delivery agreement 12: Improve the Health and Well Being of Children and Young People. Her Majesty's Stationery Office.
- HM TREASURY & DEPARTMENT FOR EDUCATION AND SKILLS (2007) *Aiming High for Disabled Children: Better Support for Families* (http://www.hm-treasury.gov.uk/media/C/2/cyp_disabledchildren180507.pdf).
- HM TREASURY & DEPARTMENT FOR EDUCATION AND SKILLS (2007b) Policy Review of Children and Young People. A Discussion Paper (http://hm-treasury.gov.uk/media/5/C/cyp_policyreview_ypversion.pdf).
- MCCARTHY, J. & BOYD, J. (2002) Mental health services and young people with intellectual disability: is it time to do better? *Journal of Intellectual Disability Research*, **46**, 250–256.
- McINTYRE, L. L., BLACHER, J., BAKER, B. L. (2002) Behaviour/mental health problems in young adults with intellectual disability: the impact on families. *Journal of Intellectual Disability Research*, **46**, 239–249.
- MENCAP (2004) *Treat Me Right! Better Healthcare For People With a Learning Disability* (http://www.mencap.org.uk/download/treat_right.pdf).
- O'HERLIHY, A., WORRALL, A. & BANERJEE, S. (2001) National in-patient child and adolescent psychiatry study NICAPS. Royal College of Psychiatrists Research Unit.
- PRIME MINISTER'S STRATEGY UNIT (2005) *Improving the Life Chances of Disabled People*. Final report, January 2005 (<http://www.cabinetoffice.gov.uk/upload/assets/www.cabinetoffice.gov.uk/strategy/disability.pdf>).
- RUSSELL, P. (2003) 'Access and achievement or social exclusion?' Are the government's policies working for disabled children and their families? *Children and Society*, **17**, 215–225.
- STROMME, P. & DISETH, T. H. (2000) Prevalence of psychiatric diagnoses in children with mental retardation: data from a population based study. *Developmental Medicine and Child Neurology*, **42**, 266–270.
- TONGE, B. & EINFIELD, S. (2000) The trajectory of psychiatric disorders in young people with intellectual disabilities. *Australian and New Zealand Journal of Psychiatry*, **34**, 80–84.
- WHITAKER, S. & READ, S. (2006) The prevalence of psychiatric disorders among people with intellectual disabilities: an analysis of the literature. *Journal of Applied Research in Intellectual Disabilities*, **19**, 330–345.
- WILLIAMS, C. & WRIGHT, B. (2003) Learning Disabilities Services. In *Child and Adolescent Mental Health Services: An Operational Handbook* (eds G. Richardson & I. Partridge). Gaskell.
- YORK, A. & LAMB, C. (2005) *Building and Sustaining Specialist CAMHS. Workforce, Capacity and Functions of Tiers 2, 3 and 4 Specialist Child and Adolescent Mental Health Services Across England, Ireland, Northern Ireland, Scotland and Wales*. Royal College of Psychiatrists (http://www.rcpsych.ac.uk/pdf/str_CAMHS_sep05.pdf).

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