PSSRU
Personal Social Services
Research Unit

www.PSSRU.ac.uk

Downloaded publication in Acrobat format

The PSSRU retains the copyright in this publication.

It may be freely distributed as an Acrobat file and on paper, but all quotations must be acknowledged and permission for use of longer excerpts must be obtained in advance.

We welcome comments about PSSRU publications. We would particularly appreciate being told of any problems experienced with electronic versions as otherwise we may remain unaware of them.

Email: pssru_library@kent.ac.uk

Disabled children and their families: the research evidence

Jennifer Beecham

PSSRU Discussion Paper 1708
March 2001

The **PERSONAL SOCIAL SERVICES RESEARCH UNIT** undertakes social and health care research, supported mainly by the Department of Health, and focusing particularly on policy research and analysis of equity and efficiency in community care, long-term care and related areas — including services for elderly people, people with mental health problems and children in care. Views expressed in PSSRU publications do not necessarily reflect those of funding organisations. The PSSRU was established at the University of Kent at Canterbury in 1974, and from 1996 it has operated from three branches:

University of Kent at Canterbury, Cornwallis Building, Canterbury, Kent, CT2 7NF
London School of Economics, Houghton Street, London, WC2A 2AE
University of Manchester, Dover Street Building, Oxford Road, Manchester, M13 9PL

The PSSRU Bulletin and publication lists are available free from the librarian at the PSSRU in Canterbury (01227 827773; email pssru_library@kent.ac.uk) and on the PSSRU website.

Email: PSSRU@kent.ac.uk Website: http://www.pssru.ac.uk

30 March 2001

Disabled Children and their Families: The Research Evidence

Paper prepared for:
SPRU/DH Seminar, Moat House, York, 28-29 March 2001.

Costs and cost effectiveness issues

Introduction

Cost and cost-effectiveness studies should be underpinned by a clear understanding of economic theory and economic evaluative techniques. There is quite an extensive body of literature exploring the application of these approaches in health and social care contexts (see, for example, Netten and Beecham, 1993; Knapp, 1995; Drummond et al., 1998). Many of the existing studies consider services and supports for adults but they provide a good basis for taking similar research forward in child care.

General cost issues: what we have and what we don't have

We can estimate the unit costs (per day, per hour, per contact) for many of the services used by children with disabilities from nationally applicable data found in *The Unit Costs of Health and Social Care* annual compilations (see, for example, Netten and Curtis, 2000).

However, we do not have good unit cost information for some of the specialist and/or expensive services disabled children may use such as residential care, foster care, respite care or medical interventions. For many services types the name or label (say, keyworker) hides a wide range of different components and ways of working; it is rarely clear what this 'black box' contains.

There is a small body of evidence on the extra family-borne costs of childhood disability (see, for example, JRF 1998). There is no information on the opportunity costs of informal or family care.

With the exception the data provided by the CiN survey and a few research publications we do not know how much of these services disabled children and their families use and in what combinations of services. Without these data we cannot estimate the costs of supporting individual children: just as families are different, so will their service needs be different and so will the outcomes generated by receiving services be different. We should, therefore, expect the costs of supporting children to vary.

The CiN survey only covers information about activities and costs to social services departments. The costs of services provided by other organisations (health, education, and independent sector) are particularly important when considering complex packages of support for disabled children living with their families.

There appears to be little in the way of cost (or cost-effectiveness) information which compares costs for people living in different types of placement or in facilities managed by the different provider sectors.

There appears to be little information on the different support costs of different client groups. For example, we might be interested in costs by diagnosis, type of disability, age, gender, or ethnicity.

Finally, we can ask what are the costs of doing nothing? What if no services and supports were provided to disabled children and their families? These costs are very high in terms of parents' and children's emotional and physical well-being. They might be high in financial terms as families breakdown and request that their children are looked after by the local authority. There are also the future costs to consider. We know a little about the adult consequences of childhood mental health problems (Knapp, 1997). In learning disabilities we might gain some insight through follow-ups of adults discharged from long-stay. We know that many people entered hospital care as young children and may have had reduced opportunities to improve their life-skills. The support costs in the community even twelve years after discharge can be very high (research due to report this year).

Summaries of published information relating to the comprehensive costs of care are given below.

The costs of supporting children with learning disabilities

A re-analysis of OPCS disability surveys, including adjustment for the mid-1990s balance of care, found that 93 per cent of children lived in ordinary households (Kavanagh and Opit, 1998). Average weekly costs for children (0-16 years) resident in private households was £330 per week at 1994-95 prices. Fifty-four per cent of costs accrued to education services, 34 per cent to the family, 7 per cent to primary and secondary health care, and 4 per cent accrued to social care services. For children in communal establishments, the average weekly cost of the placement and other service use was between £554 (private residential homes) and £1128 in local authority residential homes.

A study of 111 children with severe learning disabilities showed slightly different rates of use for many services than in the OPCS study (Beecham et al, 2001). In particular, a major increase in the number of children receiving speech therapy and a decrease in the level of use of specialist nurses were found. Seventy per cent of the children (age 4 – 11) had at least one behaviour problem that parents reported would be unacceptable in public (see also Quinne and Pahl, 1989). Domestic support workers, physiotherapists and speech therapists were the only services to provide regular weekly support. Respite care was highly valued and used by 34 families (Chadwick et al, forthcoming). Average annual support costs (1997-98 prices) £15,700 (range was £7000 to £34000), slightly lower than found in the OPCS survey but family-borne costs were not included. Seventy per cent of these costs were associated with attending school (on average £11000 per annum), and 15 and 13 per cent for health and social care services respectively.

Crowther et al. (1998) investigated the costs of schooling for children with moderate or more severe learning disability and those with additional behavioural or sensory/medical characteristics (1996-7 prices). Broadly speaking, pupils with more severe needs received more resources but the degree of weighting was often very large and the range of costs within the 8 LEAs studied very wide. School costs for pupils with severe learning disability varied between £1700 and £9700 and were generally found to be lower in mainstream than in special schools.

The costs of supporting children with physical disabilities

Although the general cost comments apply to this client group as well I can find much less information that report the costs of supporting children with physical disabilities. Some data are available on rates of service use (see, for example, Sloper and Turner, 1992; Gordon et al., 2000; Beresford, 1995). Three small studies are summarised below.

Three children with physical and learning disabilities were studied within the *Care in the Community Initiative* evaluation (Knapp et al., 1992). Support costs were £583 per week at 1986-87 prices. Seventy per cent of the costs were absorbed by the accommodation and living costs. The three young people living in their own house had flexible 24-hour staffing. The service was funded through the transfer payment from the long-stay hospital but managed by the social services department. Education services absorbed a further 22 per cent of the total costs.

A more recent study reports average annual support costs for a representative sample of young adults with HCP at £13000 (range £5600-£40,000). Forty-three per cent of the total costs were disability-related. Support costs were almost 50 times higher for children with associated conditions such as epilepsy or poor psychological functioning when compared to supporting children with simple hemiplegia whose extra costs related to their physical disabilities (Beecham et al., 2001).

There may be as many as 6000 technology-dependant children in the UK. One study investigate the circumstances of 24 such children living with their families or waiting for discharge from hospital (Glendinning et al., 2000). Support costs often exceeded £100000 per annum. Families received support from many organisations and professionals but it was often uncoordinated. The supply of equipment and drugs was often poor and disputes over who would fund these items were common.

Cost-effectiveness issues

Almost without exception the studies highlighted above are cross-sectional. At its most basic level a study to assess relative cost-effectiveness requires

- a *follow-up* component (have children ‘improved’[1] along relevant dimensions?) and
- a *comparative* component (does Support A work better than Support B?).

Adding a cost component to an effectiveness study allows us to find out

- if Support A improves children to the same extent as does Support B, is it less expensive? or,
- if, say, Support A works better, can it be provided at the same cost as Support B?

I have found no UK cost-effectiveness research relating to support for children with disabilities. Given the lack of evidence on effectiveness of treatments (Beresford et al., 1998) this is perhaps not surprising. The field most likely to generate information at the moment is

---

[1] Improved is used here to indicate any outcome measure(s) including client or parent preferences, quality of life and stress as well as measures of ability, behaviour etc. Similarly, the word Support is used to indicate any type or combination of treatments, services and supports.

in studies of interventions for children with learning disabilities who also have behavioural or mental health problems although there is one study underway of ventilator dependent children. There are also a few service (not costs) evaluations funded under other research initiatives such as the NHS R&D MCH or HTA programmes, for example, physiotherapy for children with HCP and a study of different ways of providing speech therapy.

A possible framework for identifying areas in which to study cost-effectiveness would be to think about a series of questions (after Williams, 1974).

- **WHO:** For example, who might receive which types of services?
- **WHAT:** For example, what types of services should be provided?
- **WHERE:** Should support be provided at home? In school? By which sector?
- **WHEN:** Should early intervention be provided? Brief or prolonged support?
- **HOW:** How can services be organised? What delivery modes? How to co-ordinate care?

Finally, **WHY** is an important question. Why do services work? This is about unpacking the ‘black box’ which links inputs with outputs, costs with effectiveness. We need to pay more attention to the process of care – not just *what* works but *why* it works (Beecham and Knapp, 1995, p237). Current research on therapeutic relationships in children’s mental health services may be informative.

Some thoughts on meeting information gaps

Can we identify existing studies or data to which cost could be added? This might help update our ‘baseline’ of information.

Would the data be sufficiently robust to undertake an analysis of needs and costs: What are the associations between the two? Are we spending scarce resource sensibly?

Improved unit cost estimates are desperately required for both support services and specific interventions. CiN is useful – any other publicly available sources?

Are there typical packages of care for particular groups of disabled children?

What are the information needs for each of the agencies with major statutory responsibilities for disabled children (health, education, social services)?

We do need to know which services work for whom and at what cost. Which support services or intervention should we focus on first? Perhaps those used often and by many children and families? Perhaps those which are most expensive?

The mixed economy, markets and market management?

The costs of prevention?

Selected bibliography

General cost and cost-effectiveness

Beecham, J. (2000) *Unit Costs - Not Exactly Child's Play: A Guide to Estimating Unit Costs for Children's Social Care.* Joint publication from the Department of Health, Personal Social Services Research Unit and Dartington Social Care Research Unit.

Beecham, J. and Knapp, M. (1995) Mental health economics: unfinished business, in M. Knapp (ed.) *The Economic Evaluation of Mental Health Care*, Arena, Aldershot, 229-242.

Drummond, M., Stoddart, G. and Torrance, G. (1997) *Methods for the Economic Evaluation of Health Care Programmes*, Oxford University Press, 2nd edition.

Hall, D. and Brazier, J. (1998) *Purchasing Community Child Health Services: How and How Much?* Executive summary available at http://www.doh.gov.uk/ntrd/rd/commiss/

M. Knapp (ed. 1995) *The Economic Evaluation of Mental Health Care*, Arena, Aldershot.

Netten, A. and Curtis, L. (2000) *The Unit Costs of Health and Community Care 2001*, Personal Social Services Research Unit, University of Kent at Canterbury.

Netten, A. and Beecham, J. (eds;1993) *Costing Community Care: Theory and Practice*, Ashgate, Aldershot.

Children with learning disabilities

Beecham, J., Chadwick, O., Fidan, D. and Bernard, S (2001) *Meeting the needs of children with severe learning disabilities*, submitted. Results of a survey of 111 children with severe learning disabilities who live in three London Boroughs. They were aged between four and 11 years and 70 per cent have at least one behaviour problem that parents reported would be unacceptable in public.

Chadwick, O., Beecham, J., Piroth, N., Bernard, S. and Taylor, E. (2001) Respite care for children with severe learning disabilities and their families: Who needs it? Who receives it? *Child and Psychology Review*, forthcoming.

Crowther, D., Dyson, A., Elliott, J. Milward, A. (1998) *Costs and Outcomes for Pupils with Moderate Learning Difficulties (MLD) in Special and Mainstream Schools*, Research Report No. 89, DfEE, London. Investigated the costs of schooling for children with moderate or more severe learning disability and those with additional behavioural or sensory/medical characteristics. Special schools are found to be consistently more expensive than special needs units in mainstream schools or mainstream schools for similar pupils (1996-7 prices). School outcomes were identified (SATs, screening tests, IEP outcomes) but not integrated with the costs.

Kavanagh S. and Opit, L. (1998) *The Cost of Caring: The Economics of Providing for the Intellectually Disabled*, Politea Social Science Research Series, London. Re-analysis of OPCS disability surveys, including adjustment for the mid-1990s balance of care. Support costs for both adults and children with learning disabilities (mental handicap) are estimated.

Kavanagh S. and Opit, L. (1999) The prevalence and balance of care for intellectual disability: secondary analyses of the OPCS disability surveys, *Journal of Applied Research in Intellectual Disabilities*, 12, 2, 127-148.

Flynn, M., Cotterill, L., Hayes, L. and Sloper, T. (1996) *A Break with Tradition: The Findings of a Survey for Adult Citizens with Learning Disabilities in England,* National Development Team, Manchester. Even though this is a study of adult services it highlights the diversity or care delivery modes that may be used as respite care and the tremendous cost variations that are likely to ensue as people use respite care. Nine services were visited with hourly costs between £11 and £18 (1995 prices?)

Prewett, B. (1999) *Short-term break, Long-Term Benefit: using Family-Based Short breaks for Disabled Children and Adults*, JUSSR and Community Care Magazine. Two hundred and four schemes studied. A typical user is provided with one twelve-hour session per week at a per capita cost of £1767 for children and £1407 for adults (1998 prices?).

Quinne, L. and Pahl J. (1989) *Stress and Coping in Families Caring for a Child with Severe Mental Handicap: A Longitudinal Study,* Centre for Health Services Studies, University of Kent.

Children with physical disabilities

Beecham, J., O'Neill, T. and Goodman, R. (2001) Supporting young adults with hemiplegia: services and costs, *Health and Social Care in the Community*, 9, 1, 51-59. Average annual support costs for a representative sample of young adults with HCP are £13, 000 (£5600-£40,000). Forty-three per cent of the total costs were disability-related. Support costs were almost 50 times higher for young adults with associated conditions such as epilepsy or poor psychological functioning when compared to the costs of support for young adults with simple hemiplegia.

Beresford, B., Sloper, P., Baldwin, S. and Newman, T. (1998) *What works in services for families with a disabled child?* Barnardo's, London.

Beresford, B. (1995) *Opinions: A National Survey of Parents Caring for a Severely Disabled Child*, Joseph Rowntree Foundation, York.

Glendinning, C. and Kirk, S. with Guffrida, A. and Lawton, D. (1999) *Supporting Families Caring for a Technology-Dependant Child in the Community,* National Primary Care Research and Development Centre, Manchester.

Gordon, D., Parker, R., Loughran, F. with Heslop, P. (2000) *Disabled Children in Britain*, HMSO, London.

JRF Findings (1998) *The Costs of Childhood Disability,* Joseph Rowntree Foundation, York

Knapp, M., Cambridge, P., Thomason, C., Beecham, J., Allen, C., and Darton, R. (1992) *Care in the Community: Challenge and Demonstration*, Avebury, Aldershot.

Morris, J. (1999) *Hurtling in a Void: Transition to Adulthood for Young People with Complex Health and Support Needs*, Joseph Rowntree Foundation and Pavillion Publishing, Brighton.

Morris, J. (1998) *Still Missing? Disabled Children and the Children Act*, The Who Cares? Trust, London.

Roberts, K. and Lawton, D. (1999) Financial assistance for families with severely disabled children and transport costs, *Children & Society*, 13, 5, 333-345.

Sloper, P. (1999) Models of service support for parents of disabled children. What do we know? What do we need to know?, *Child: Care, Health and Development*, 25, 2, 85-99.

Sloper, P. and Turner, S. (1992) Service needs of families of children with severe physical disability, *Child: Care, Health and Development*, 18, 259-282.

Children with mental health problems

Byford, S., Harrington, R., Torgerson, D., Kerfoot, M., Dyer, E., Harrington, V., Woodham, A., Gill, J. and McNiven, F. (1999) Cost-effectiveness analysis of a home-based social work intervention for children and adolescents who have deliberately poisoned themselves: the results of a randomised controlled trial, *British Journal Psychiatry*, 174, 56-62. The study found that a family based social work intervention for children and adolescents who have deliberately poisoned themselves is equally as cost-effective as routine care alone and provides greater parental satisfaction.

Harrington, R., Peters, S., Green, J., Byford, S., Woods, J. and McGowan R. (2000) Randomised comparison of the effectiveness and costs of community and hospital based mental health services for children with behavioural disorders, *British Medical Journal*, 321, 1047-1050. The study showed that the location of CAMH services (community or hospital) might be less important than the range of services provided. Effective treatment for parents' mental health problems should be provided.

Jarbrink, K. and Knapp, M (2000) The economic impact of autism in Britain, *Autism*, 5, 1, 7-22.

Knapp, M. (1997) Economic evaluations and interventions for children and adolescents with mental health problems, *Journal of Child Psychology and Psychiatry*, 38, 1, 3-25. Summarises evidence and issues from UK, other European countries and USA. Highlights gaps in information.

Knapp, M. and Henderson, J. (1999) Health economics perspectives and evaluation of child and adolescent mental health services, *Current Opinion in Psychiatry*, 12, 1999, 393-397. Reviews recent publications in the field.

Knapp, M., Scott, S. and Davies, J. (1999) The cost of anti-social behaviour in younger children: a pilot study of economic and family impact, *Clinical Child Psychology and*

Psychiatry, 4, 4, 457-473. Provides details and comprehensive costs ten children with conduct disorder; a pre-cursor to an intervention and cost-effectiveness study of parent training.

Dr Jennifer K Beecham
PSSRU, University of Kent; CEMH, Institute of Psychiatry