Guide to Using Psychotropic Medication to Manage Behaviour Problems among Adults with Intellectual Disability

Technical Document

Shoumitro Deb, MBBS, FRCPsych, MD, Clinical Professor of Neuropsychiatry and Intellectual Disabilities
and Gemma L. Unwin, BSc(Hons).

University of Birmingham,
Division of Neuroscience,
Department of Psychiatry, UK.

Acknowledgments: Thanks to the Guideline Development Group members – Gill Bell, Sabyasachi Bhaumik, David Branford, Rob Chaplin, David Clarke, Chris Dale, Caroline Lee, Suzanne Robinson, Ashok Roy, Florence Simon, Ray Smart, Biza Stenfert Kroese, Caron Thomas, Miriam Wilcher, and Linda Woodcock

www.LD-Medication.bham.ac.uk

November 2006

Supported by
BIG LOTTERY FUND
UNIVERSITY OF BIRMINGHAM
The Royal College of Psychiatrists
Let Wisdom Guide
MENCAP
Understanding learning disability

Guide to Using Psychotropic Medication to Manage Behaviour Problems among Adults with Intellectual Disability

Technical Document Section 7: Health Economic Evaluation

Shoumitro Deb, MBBS, FRCPsych, MD, Clinical Professor of Neuropsychiatry and Intellectual Disabilities
and Gemma L. Unwin, BSc (Hons).

University of Birmingham,
Division of Neuroscience,
Department of Psychiatry, UK.

Acknowledgments: Thanks to the GDG, particularly Suzanne Robinson (Health Economist), Florence Simon, Caroline Lee, Miriam Wilcher, Ashok Roy and David Clarke.

www.LD-Medication.bham.ac.uk

November 2006

Supported by
BIG LOTTERY FUND
UNIVERSITY OF BIRMINGHAM
The Royal College of Psychiatrists
Let Wisdom Guide
MENCAP
Understanding learning disability

Introduction

Scarcity of health care resources is a feature of all health care systems; such scarcity means that important choices around the alternative uses of resources need to be made. Economic analysis attempts to compare the costs and benefits of alternative interventions (Drummond 1995). In order to conduct a full economic evaluation, details on both the costs and benefits of the intervention in question are needed. Thus, comparing costs of one treatment with another, without any evidence on outcomes, does not constitute an economic evaluation (Knapp, 2004).

The original aim of the present project was to use existing published data to evaluate the cost effectiveness of treatment for adults with behaviour problems and a learning disability. This would allow for greater understanding of the cost implications of the use of medication to manage adults with behaviour problems and a learning disability. The intention was to compare the relative costs and outcomes for the use of medication alone, non-medication based interventions alone, and both medication and non-medication based interventions together (see Figure 1). However, the literature review identified a lack of health economics data on learning disability and treatment and more specifically treatment for behaviour problems in this group. In addition, proper randomised controlled trials comparing different treatments and providing information on what proportion of those on one treatment improved compared to those on another is also required. Furthermore, at present, there is no available data on the economic evaluation of different treatments for behaviour problems in adults with a learning disability. Therefore, the information presented here needs to be interpreted with caution; it does not constitute a definitive economic evaluation and is intended to provide some indication of the different elements of cost and outcome involved with providing different treatments.

Controversy exists surrounding the difficulties of costing certain features that are involved in the treatment of an individual. It is very difficult to precisely cost any non-medical input into treatment, for example, psychologists or community nurses. Hourly rates will vary across NHS Trusts and it is difficult to quantify exactly how many hours of input will be needed in each case. Furthermore, it is very difficult to quantify the cost of caring and the cost for carers and how much input these individuals have had and their therapeutic role in treatment (this issue will be discussed in more detail later in the section).

Method

A literature review was undertaken to highlight existing evidence relating to the costs associated with certain medication treatments. Particular focus was applied to studies that had undertaken some form of economic analysis including cost effectiveness analysis or cost utility analysis (see glossary). Both types of analysis incorporate both costs and outcomes. The difference in the types of evaluations relates to the way the outcomes are measured. In cost-effectiveness analysis, outcomes are measured in natural units such as life years saved or events avoided, whereas, cost utility analysis measures the effects of treatment on individuals' length and quality of life. Results are usually reported in the form of cost per Quality Adjusted Life Years (QALYs).

The literature review had two strands, the first was a focused review based on searches for research articles that included costs relating to the use of medication in the management of behaviour problems in adults with a learning disability. The aim of the second review was to identify studies that had explored costs relating to services (either health and or social care) for individuals with a learning disability and behaviour problems. These studies did not necessarily have information on the cost of medication treatment and the relative outcomes.

Furthermore, in response to the lack of research papers pertaining to the health economics of the management of behaviour problems in adults with a learning disability, real life case vignettes were developed by the Guideline Development Group (GDG). These case vignettes were designed to provide some information on the relative costs and outcomes for adults with a learning disability who receive medication for the management of a behaviour problem. However, the information contained within the case studies is not intended to guide practice, rather, it is intended to give an indication of issues surrounding the cost of managing behaviour problems. It therefore needs to be interpreted with caution.

Literature Review 1: Medication management of behaviour problems

The literature review followed a similar methodology to the systematic review reported in Section 3 of this technical guide.

Type of studies considered
Any study that has conducted some form of economic analysis including full economic evaluations (i.e. cost effectiveness analysis and cost utility analysis), and partial cost analysis.

Type of participants and intervention
The criteria used in the systematic review (Section 3) were adopted in this literature search.

Databases used
Medline (1990 to March 2005)
Embase (1990 to March 2005)

Search Terms
The search strategy was adapted to each of the databases. It included all the terms used in the systematic review (Section 3), with the addition of the following terms:

1.cost analy$
2.cost effectiveness$
3. cost utilit$
4. cost benefit$
5. QALY$
6. economic evaluation$
7. or/1-6

Inclusion criteria
Any form of cost analysis or cost effectiveness analysis relating to the medication treatment of behaviour problems in adults with a learning disability.

Results
Only 4 papers were identified, all of which were excluded, because they had no information on primary or secondary cost data. Therefore, there was no cost information that could be used to inform a health economic analysis of the medication management of behaviour problems in adults with a learning disability.

Literature Review 2: General healthcare cost information

Due to the lack of data, specifically relating to medication-based intervention, a second literature search was undertaken, this was less systematic in its approach and involved identifying cost information that related to any health care costs associated with individuals with a learning disability. This included searches of the World Wide Web, Medline, and hand searching of the health economist's own literature collection. Furthermore, cross-referencing of reference lists was undertaken to ensure that all the relevant articles were identified. The inclusion criteria for this search was again any study that had carried out some form of cost analysis on healthcare for adults with a learning disability and behaviour problems.

Results

Nine studies were identified which had collected primary cost data relating to service utilisation for people with a learning disability (see Table 1 for study details). All studies reported costs associated with an individual's care package rather than relating to individual medication costs. Details of the studies are reported below.

Summaries of Included Studies

Knapp et al (2005) examined the links between degree of learning disability, behaviour problems, and service utilisation, in a group of adults with a learning disability living in care accommodation in England. They carried out multivariate analyses for 930 adults and found strong links between degree of learning disability, behaviour, service utilisation and cost. The reported average weekly cost of those in care ranged from £220-£1570, however, the sample was largely derived from NHS facilities and was not randomly selected. Higher costs were associated with more severe learning disability and more severe behaviour problems. Other factors which influenced cost included sector and scale of residence. The authors did not undertake a cost effectiveness analysis as there was no data on outcomes. Hallam et al (2002) also suggested that the cost of service provision was affected by the size of residential setting, with smaller sites tending to be the most expensive. Furthermore, higher costs were associated with higher levels of learning disability and more severe behaviour problems. However, the authors did not consider evidence on outcomes for the participants in their study.

Robertson et al (2004) compared the average weekly cost of care for individuals with behaviour problems in congregate (services primarily or solely for those with behaviour problems in which over 50% of resident had behaviour problems) and non-congregate residential community-based care (services for those with a learning disability, with or without behaviour

problems in which less than 50% had behaviour problems). The costs data were collected in the UK and translated into US dollars at a rate of £1 = $1.65. The results of the study suggest that congregate provision was more costly ($121,235) than non-congregate provision ($96,268) and the authors conclude that non-congregate residential supports are more cost effective.

The costs in the study by Robertson et al (2004) were lower than those reported by Felce et al (1998) who reported relative costs, processes and outcomes for people with severe learning disability and severe behaviour problems in Wales across three different residential settings (family homes, new specialist community housing, and traditional services including long-stay hospitals and hostels). Felce et al (1998) suggest that the total costs of care were correlated with accommodation. Care in community housing was also more costly than that provided in the traditional setting. However, the authors argue that this may be offset by increased patient benefits. Across all three service types, the authors found no relationship between costs and severity of disability. However, they did find a relationship between costs and service quality, but the authors argue that this is largely underpinned by the considerable differences in community houses and traditional settings and this relationship ceased when each service type was considered separately.

The paper by Comas-Herrera et al (2001) outlines the average weekly costs per adult with a learning disability in residential accommodation for 930 individuals in the UK. The average costs were calculated for the following services and were as follows:

Residential accommodation	NHS: £655.97	(CI £649.56-£682.39)
	Private: £491.51	(CI £472.21-£510.80
	Voluntary: £332.00	(CI £320.66-£343.45)
Hospital services	NHS: £9.90	(CI £5.11-£14.67)
	Private: £1.13	(CI-£0.41-£2.66)
	Voluntary: £4.61	(CI-£3.09-£12.31)
Day activity	NHS: £76.84	(CI £67.99- £85.68)
	Private: £75.11	(CI £61.95-£88.28)
	Voluntary: £63.66	(CI £53.03-£74.30)
Community services	NHS: £26.19	(CI £21.84-£30.64)
	Private: 13.99	(CI 12.14-15.84)
	Voluntary: £10.89	(CI £8.52-£13.27).

People living independently or in a family home were not included in the analysis. Inclusion of this group would most certainly have affected the average cost for all services. In all cases, the costs for NHS provided services was highest, this is especially true for residential services. There was little difference in the costs for day activities across all three providers.

Local costs for residential services for people with a learning disability suggest that NHS services can be less expensive than private services. Estimates of

the yearly cost for NHS residential services are around £100,000 - £150,000 per year. However, the yearly cost for a service user of a private residential hospital could be over £150,000.

Dockrell et al (1995) completed an economic analysis of the resettlement of people with mild learning disabilities and severe behaviour problems. They focussed on a highly specialised, recently established assessment and treatment service in the southeast of England. The authors conclude that the resettlement of people with learning disabilities and behaviour problems from long-stay residential institutions to community homes provides benefits in terms of quality of life, freedom, and closer associations with the local community. However, they suggest that such benefits are as a consequence of quite high costs.

Emerson et al (2001) also identified community participation as a potential benefit of some service models. Their results suggest that for similar costs, supported living provides more positive consequences for service users, particularly in terms of resident choice and community participation than small or large group homes. However, no statistically significant differences were established between each of the rated levels of satisfaction by the service users from the supported living services and the group homes, with the participants tending to rate all the services highly.

An earlier study by Emerson et al (2000a) comparing community-based residential supports and residential campuses for people with severe and complex disabilities found similar results. Small community-based dispersed housing schemes were rated to be significantly more beneficial in terms of quality of care and quality of life for residents. However, the total costs of provision in dispersed housing schemes were significantly greater than those for the residential campuses. This difference was accounted for by the differences in direct staffing costs in the community-based services. Similarly, a lager scale study by Emerson et al (2000b) indicated that dispersed housing schemes and village communities provided a significantly greater quality of care and quality of life for residents than residential campuses. However, the adjusted comprehensive costs of service provision were 15% higher in dispersed housing schemes than in residential campuses and 20% higher than in village communities.

The above studies were of limited use to the present guideline development project. This was largely due to the relatively narrow focus of the papers, with studies tending to present cost data for individuals in residential accommodation with limited information on costs associated with those living independently, and in particular information on medication-based or non-medication based interventions, or carers.

The literature reviews identified the dearth of economic information relating to the costs associated with interventions for individuals with a learning disability and behaviour problems. Whilst, the present project recognises the need to conduct primary research on the costs associated with this group, it was beyond the remit of this project to conduct such primary research. It is

recommended that the area of health economics needs to be addressed in future learning disability research.

Case Examples

In light of the paucity of literature on the costs related to the use of medication to manage behaviour problems in adults with a learning disability, the GDG used expert opinion from within the group to develop three case examples. These real life case vignettes provide information relating to different levels of medication usage and hospital and social care services in Birmingham. Cost information was applied to the three examples. The examples include a number of resource uses including medication, inpatient hospital admission and a range of social care services.

Cost data was obtained from a number of sources:

Medication costs:	British National Formulary (BNF No. 49, March 2005), NHS Drug Tariff and pharmacist dispensing fee and container fee. Presumed that the prescription would be dispensed every month. Presumed that the medication was in the form of tablets unless stated otherwise.
Healthcare salaries/ Employment costs:	Extracted from average salaries in Birmingham, taken at the mid-point of the scales.
Bed costs:	NHS finance office.
Social Care costs:	Calculated on an average weekly rate per number of individuals using residential short break services and day support. This data was extracted by using the Care First System.

The cost year was 2005.

For the purpose of this exercise, it was not possible to quantify the costs of carer's interventions and the related carer's costs. This is discussed in further detail later in this section.

Both health and social care organisations have different criteria for eligibility of services. Health criteria are based on Continuing Care Criteria. This describes the care some people need over an extended period of time as a result of disability and accident, or illness. The care is provided for physical and/or mental health needs and may require services of the NHS and/or local authority.

Social care uses the Fairer Access to Services Banding System to determine eligibility for its services. This is broken down into four bands – critical, substantial, moderate and low. Only service users who are assessed as having critical or substantial needs under the criteria, will be eligible to receive service from social care providers.

The following case studies explore a range a costs from medication costs to inpatient hospital admission and social care costs of providing a range of services in Birmingham.

The GDG recognises that such cost analysis does not constitute a full economic evaluation and is of limited use to decision makers. However, it is felt that in light of the lack of literature in the area, the case examples illustrate some important issues relating to the relative costs associated with medication intervention in the management of behaviour problems. Furthermore, it is not possible to state whether medication treatment is more or less cost effective than provision of Health and Social care services as there is no comparative data available to complete a full cost analysis.

Case A:
Demonstrates the relatively small cost of medication and intervention from professionals. Costs escalate when behaviour worsens and care and supervision needs increase.

Introduction
A is a 22 year old man with moderate learning disability and a history of aggressive behaviour for the last 6 months.

Early History
A is the first of three children. From an early age he found it difficult to make friends and would frequently get into fights with other children. He was late in acquiring speech and the gap between him and his peers widened, as he grew older. This accompanied by his escalating aggression led to him being statemented and transferred to a school for children with moderate learning disabilities. Here his behaviour continued to cause concern and he was found to need additional supervision during school hours everyday (£270 per week; £8100 per year (30 weeks of term time)). His parents found that they had to supervise him constantly (carer costs not determined) as he would hit his younger sisters if he did not get his own way. He started receiving respite care one weekend every month to give his parents some time with their daughters (£6000 per year).

Recent History
After leaving school at the age of 19 without formal qualifications, A started attending a college for further education everyday. His teachers noticed that his aggressive outbursts started increasing especially when A was working in a large group in the workshop. On one occasion, he caused injury to a fellow pupil severe enough to need a few stitches. He was excluded from college and at this point referred to the local learning disability service.

Assessment and treatment
A was initially seen at home by a community nurse on three occasions (£50 per visit; £150 total). It was felt that A needed further assessment and he was referred to the local psychiatrist (£120). He was then diagnosed to have an autistic spectrum disorder as well as being prone to significant mood swings. He was prescribed a small dose of Risperidone (0.5mg twice a day) (£293 per year). He then was followed up in an outpatient clinic for two months at fortnightly intervals jointly by the psychiatrist (£480) and the community nurse (£144). Attempts were made to return him to college but the college staff were only willing to consider this if he received staff support during the day. This was agreed but was possible only three days a week (£220 per week; £6600 per year).

After a few days in college it was noticed that A was still unsettled in large group settings and more so at mealtimes and in noisy work environments. A referral was made to the occupational therapist who assessed him weekly over a 6-week period (£100) for any abnormalities in sensory processing. A

report was produced which recommended significant changes to the handling strategies and also changes in the environment. A was moved to a smaller group that worked in a quieter environment. He was allowed to eat on his own and it was felt that efforts needed to be made to help him understand his routine better. He was referred to a communication therapist who over 6 weekly sessions (£100 per visit; £600 total) with A and his staff devised a pictorial diary to help A understand and anticipate his day more clearly.

Follow up and review
A was visited by the community nurse every two weeks (£100) and attended a clinic for a psychiatric review every month for 3 months (£60 per visit; £180 total). He remained well and at a subsequent review it was agreed that his staffing at the college could be cut down to escorting him to and from the college only. During this time, he was provided with increased evening and weekend activities thus providing his family more time to devote to the younger children

Case B:
Demonstrates the relatively low cost of medication and assessments compared to the cost of skilled residential care. In cases where the medication can stabilise behaviour as in this case, the costs can reduce but still remain high.

Introduction
B is a 26-year-old woman with severe learning disabilities and a long history of aggressive behaviour directed towards people and property. She occasionally displays self-injurious behaviour.

Early history
B was born to a large family which had been in close contact with the local social services due to concerns with child protection. B was delayed in achieving her motor and language milestones. At the age of 4, she started attending a school for children with severe learning difficulties. At the same time, there was an increase of restless impulsive and aggressive behaviour and B was placed with foster parents as there were concerns about the ability of her biological parents to care for her.

Recent history
After moving to her new environment B continued to be aggressive to her new family as well as getting into frequent skirmishes with other children at school. She was then provided with additional staffing support in school 30 hours a week for 30 weeks a year (£270 per week; £8100 per year).

Assessment and treatment
As her problems escalated, she was then referred to the local learning disability service. She was assessed by the community nurse who over a period of 12 weekly home and school visits (lasting one hour) drew up a

behaviour programme (£20 per hourly visit; £240 total). This was then implemented at school and led to some improvement in the frequency and intensity of behaviour. After an episode of aggression aimed at the classroom helper, she was referred to the local psychology service to see if there were any emotional factors such as moving from the family home which could contribute to her behaviour. She was seen by the psychologist every week for an hour for 12 weeks (£60 per hourly visit; £720 total) and it was felt that there was no evidence that there were any emotional factors that were contributing to her behaviour.

B was eventually excluded from school aged 18 on account of her continuing aggression (carer costs not determined). She was then referred to a psychiatrist (£120) who felt that her recent exacerbation of behaviour was due to an agitated depression. She was given a mixture of Risperidone 2 mgs twice daily and Fluoxetine 20 mgs once daily (£931 and £45 per year). There was little improvement and she was eventually admitted into an assessment ward in a LD hospital. B remained in hospital for 2 years during which time she had one to one staffing on the ward and two to one staffing when she went out, about 15 hours a week (£192,000 per year (£92,000 for bed, £100,000 for additional staffing), total cost for 2 years £384,000). There she was put on Zuclopenthixol Decanoate Depot which was eventually stabilised at 300mg intramuscularly every two weeks (£174 per year). Additionally she was given Sodium Valproate 600 mgs twice daily to try to stabilise her mood (£132 per year).

She was then moved to another ward and a different clinical team specialising in rehabilitation. There she was screened for autistic spectrum disorder and for ADHD. She met the criteria for ADHD. This diagnosis was then confirmed by reviewing her history. She was then commenced on Atomoxetine and stabilised on 72 mgs per day (£2,658 per year). She showed a marked reduction in her aggressive outbursts and was able to engage in her day activities. The staffing levels dedicated to her were decreased over a period of 6 months and over that time her Zuclopenthixol Depot, Sodium Valproate and Fluoxetine were discontinued.

Follow up and review

B was discharged from hospital nearly 6 months ago. She lives in her own house supported by staff. She is escorted by staff (one to one) when outside the home (£240,000 per year). She is now attending college 4 days a week and has gradually established contact with her foster family who could not easily visit her in hospital.

Case C:
Demonstrates the benefit of treatment leading to a marked reduction in problem behaviour. Unfortunately, side effects caused major difficulties, and led to a cessation of medication with an exacerbation of problem behaviour. Introduction of other medication did not lead to significant improvement. The costs of the medication were relatively small compared to the difficulties caused by the side effects, and the relapse to previous behaviours on stopping medication.

Introduction
C is a 17 year old young man with moderate learning disability associated with fragile X syndrome who resides at a special school during school terms.

Early History
Normal pregnancy and delivery. General delay in skill acquisition, had the skills of an 18 to 24 months child at 3 years 6 months, when a diagnosis of fragile X syndrome was made. Behavioural problems and problems with attention and concentration noted from this age onwards. Parents found reprimand and other usual strategies to deal with problem behaviours ineffective. Moved from non-residential special school to residential special school (£65,000 per year) at the age of 9 years. Parents separated. Seen 3 monthly from the age of 3.5 years to 13 years by Consultant Paediatrician (£3,061.76).

Recent History
While at residential school, methylphenidate was prescribed in doses up to 10 mgs three times a day (£216 per year) by paediatrician for behavioural problems and inattention. Limited impact on behaviour. Mother found it difficult to cope with behaviour during weekends and school holidays, C often destructive of property and aggressive to her.

Assessment and Treatment
In 2000 referred to Consultant in Learning Disability Psychiatry and seen since then every 3 months in school clinic (£1,472). Methylphenidate withdrawn and stabilised on risperidone 0.5 mgs twice a day (£293 per year). Marked improvement in attention, concentration and behaviour in the school and home settings. Now few problems during school holidays. Good educational progress.

In 2004 (age 16 years) reassessed urgently. “Flipping” his head backwards, craning his neck, grimacing, repeatedly putting his left hand to his mouth and stroking it and many other abnormal head and neck movements.
Risperidone reduced and withdrawn over 5 days.
Within 3 weeks mother reporting major behavioural problems. Destroyed items in caravan, pulled hubcaps off cars, threw objects (including a kettle of boiling water).
Urgent review by paediatrician (£120) and referral to paediatric neurologist for assessment in paediatric movement disorders clinic (£120). It was agreed that

he had dyskinetic movements probably related to risperidone.

Re-started on methylphenidate 10 mgs three times a day (£216 per year). No improvement in behaviour. Mother again reported having major problems with aggression and property destruction in school holidays. Referral to intensive support team, assessed and advice provided to mother about dealing with aggression - 2-hour initial assessment and 5 follow-up visits (£230.40). Social services funded a support worker half a day per week during the summer holiday (£1,422.40 per year) and provided 2 days per week respite care in social services staffed community respite unit for children (£3,413.76 per year).

Follow-up and Review
C has recently had a trial of propranolol 40 mgs daily (£4.86 for 3 months; £14.58 total) with no benefit, and has just started atomoxetine, currently in a dose of 20 mgs daily (£1,322 per year). There may have been some slight improvement. The arrangements put in place to support his mother over the summer holiday (support worker, respite care, etc) remain in place. He has never re-gained the improvement in attention, concentration and behaviour noted while he received risperidone.

The case studies provide an indication of the costs of managing behaviour problems in adults with a learning disability. However, they represent incomplete and inaccurate estimates of costs and therefore the data should be interpreted with caution. The case studies are not intended to guide practice, rather, promote consideration of the complexity of costs involved with providing treatment.

Carer's Costs

There are many difficulties associated with applying costs to aspects of health care in relation to adults with a learning disability and behaviour problems. The multifaceted and fluid nature of health and subsequent costs confounds the process of economic analysis of certain treatment pathways. This issue is particularly relevant in the field of behaviour problems which function within an environment and therefore are responsive to and rooted in the physical and social context.

In addition to the direct health care costs of managing behaviour problems in an adult with a learning disability, there are many other costs incurred that are very difficult to quantify. One such cost particularly pertinent to a population with learning disability and behaviour problems is that of carers' costs. There are currently an estimated 6 million carers throughout the UK (Department of Health, Social Services and Public Safety, 2001) who provide a wide range of care, from cleaning and shopping, to washing and bathing, to performing medical tasks such as administering medication. Due to the hugely varying tasks performed by carers and the unpredictable and complex nature of care, it is extremely problematic to calculate a definitive cost of caring.

A common method used to provide an approximation of the cost of caring is to calculate the cost of replacement care. In order to establish the total cost of replacement care for carers throughout the UK, Carers UK (2002) determined an estimated hourly wage for carers then applied it to the number of reported hours spent caring for each carer in the UK. To arrive at the cost for replacement care, Carers UK took an average of the hourly rate of home care in the independent sector and that of local authority care. The proposed rate of £9.95 per hour attempted to strike a balance between more costly care, for example nursing tasks, and care purchased on different markets. Nevertheless, this estimate may be rather conservative with the Performance Assessment Framework from the Department of Health (2001) anticipating a gross hourly unit cost of £11.46.

However, the direct cost of replacement care does not account for all the costs related to caring. There are many other indirect costs associated with caring that greatly affect the lives of carers. Research has suggested that over half of all carers providing a substantial amount of care have been treated for a stress related disorder with half of the same group having also sustained a physical injury due to lifting or handling the disabled person (Henwood, 1998). Moreover, recent research suggests that carers endure high levels of psychological distress, including anxiety, depression, loss of confidence and self-esteem when compared to non-carers (Hirst, 2004). The treatment of such conditions may also generate an additional cost for health services.

Carers can also incur financial implications as a result of their caring. Holzhausen and Pearlman (2000) suggested from their survey that almost

80% of respondents felt they were financially worse off since becoming a carer. Furthermore, the cost of caring can effect the national economy in terms of lost tax revenue, for example, if carers cannot return to or sustain employment due to ill health as a result of caring. The impact on the economy and the cost for carers will vary depending on the carer's original earning.

For many, caring for a friend or family member is a twenty-four hour a day, seven days a week occupation. It is extremely difficult to accurately calculate the cost of caring, as there are many factors to take into account ranging from the economic value of carers' to the impact on quality of life for carers.

Discussion

The lack of available data made it impossible to conduct either a full or partial economic evaluation. Therefore, it cannot be concluded whether particular medication based interventions are more cost effective than others, likewise whether medication based interventions are more or less costly than non-medication based interventions. It is suggested that the health economics of the management of behaviour problems in adults with a learning disability is an appropriate area for future research so that management and service decisions can be informed. It is particularly important that the cost effectiveness of different interventions is determined not only by a reduction in the frequency and severity of the target behaviour but also in an improvement in quality of life for the individual, their families and carers.

The research literature identified as part of search two largely focussed on establishing the costs of different services, more specifically residential services, and evaluating the cost effectiveness of these services. The research identified suggests that higher service costs are associated with more severe learning disability, more severe behaviour problems and care in the community as opposed to traditional campus residential facilities for those with severe behaviour problems. However, the relationship between these variables is for from clear with other studies finding no relationship. Overall, few of the studies completed a full cost effectiveness analysis or cost utility analysis, fully taking into account quality of life, quality of care and cost per service package compared with another.

Hallam and Knapp (in Emerson et al, 2004) discussed the economics of learning disability. They acknowledge that “the costs of supporting individuals with intellectual disabilities are often substantial and spread widely between agencies, service users and families” (p 619). They also identify a need to measure and compare the costs and outcomes of different services, intervention and packages to reliably inform policy and practice for people with a learning disability. Therefore, Hallam and Knapp (2004) call for more good quality research to be undertaken that carries out economic evaluations of different services for people with a learning disability. They suggest that in designing such studies, special attention needs to be paid to how costs and outcomes are measured.

Table 1: Summary of Studies

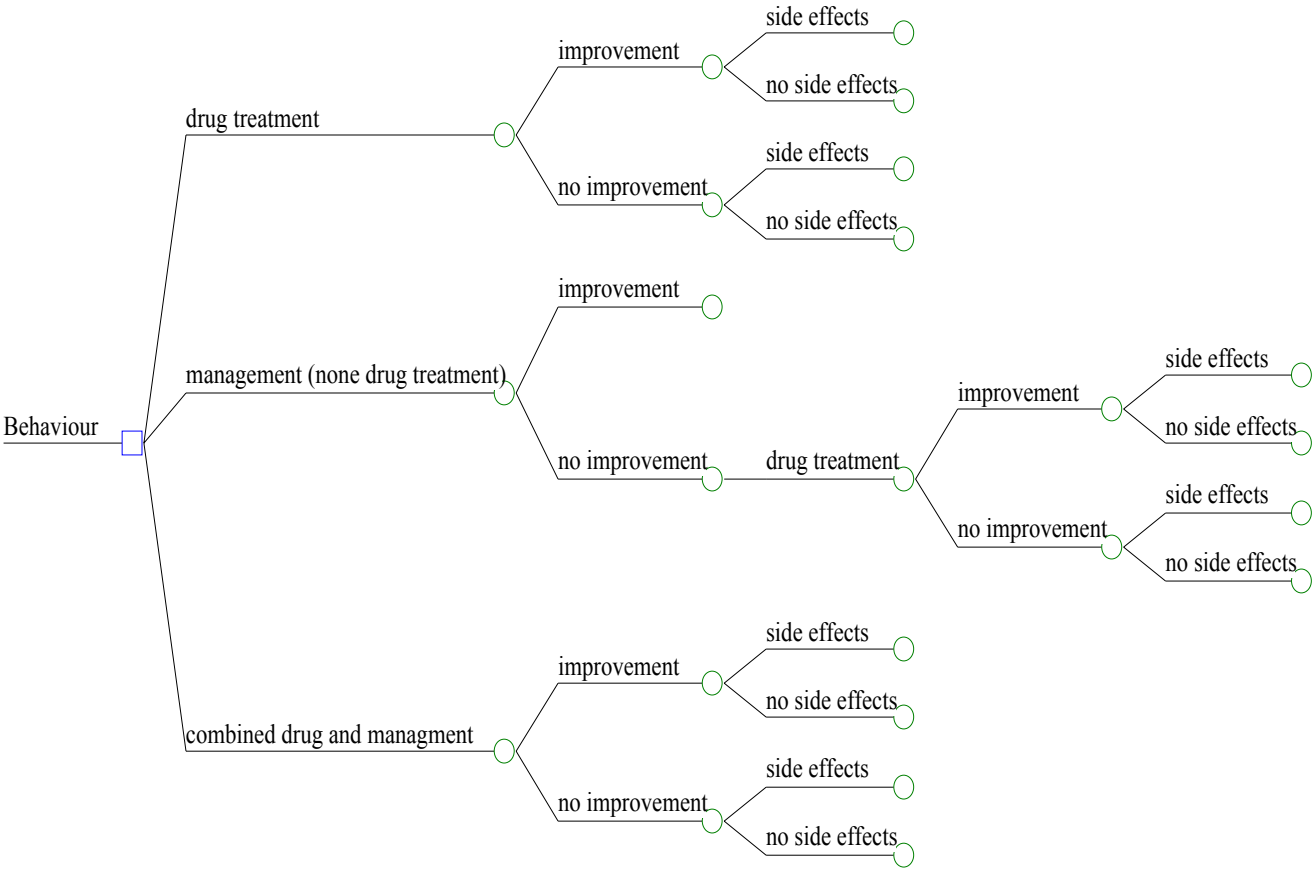
Author (year), Country	Setting	Type of economic evaluation	Cost data Year and type of currency	Primary outcome	Result	Comment
Knapp et al (2005) UK	Residential care home	Cost analysis	Not Specified	Average cost of those in care per week	Range £220-£1570	The study showed that higher costs were associated with more severe disabilities.
Hallam et al (2002) UK	Various community and residential settings	Cost analysis	1999/2000 Great British Pounds	Average cost for residential accommodation per week	Mean cost of accommodation: £637 in village communities, £931 in residential campuses, £902 in dispersed housing schemes. Median cost of supporting study participants: £542 in village communities, £975 in residential campuses, £890 in dispersed housing.	The cost was affected by the size of residential setting. Smaller sites tended to be more expensive.
Robertson et al (2004) UK	Community based residential care (congregate provision vs non-congregate provision)	Cost analysis	Year Not Specified US Dollars	Average weekly care costs	Congregate provision range: $49,335-$175,633, Non-congregate provision range: $44,702 to $129,815 Adjusted means congregate $121,235 and non-congregate $96,268	Costs in congregate provision were significantly higher than those in non-congregate settings
Felce et al (1998) UK	Community housing, traditional services	Cost analysis	1995/ 1996 Great British Pounds	Average cost of service packages for 3-month period	Traditional settings £11,464, community houses £22,898,	Total costs were significantly correlated with accommodation. Costs were moderately associated with severity of disability. Community housing was more costly than the traditional setting, However, the authors suggest this may be off set by the increased quality of life benefits derived by participants.
Comas-Herrera et al (2001), UK	Residential care home	Cost analysis	Year Not Specified Great British Pounds	Average costs for residential accommodation per week	NHS £655.97 Private £491.51 Voluntary £332.00	People living independently or in a family home were not included in the analysis. Costs for NHS provided services higher than those provided by the private or voluntary sector.

Author (year), Country	Setting	Type of economic evaluation	Cost data Year and type of currency	Primary outcome	Result	Comment
Dockrell et al (1995) UK	Community and residential services	Economic analysis	1989/1990 Great British Pounds	Cost per client per year and quality of life	Better quality of life opportunities for people with a learning disability are associated with higher costs. Community placements were associated with approximately 25% additional expenditure than previous placements (for example long-stay NHS/private residential institutions, prison, NHS/private hospital)	The resettlement of people from long-stay residential institutions to community homes is associated with quite high costs, however, it is associated with benefits in terms of quality of life, freedom and closer associations with he community.
Emerson et al (2001) UK	Supported living residences and group homes	Economic analysis	1997/1998 US Dollars	Cost per client per week and a range of other quality of life indicators	Accommodation costs: Supported living; $1592 Small group homes; $1302 Large group homes; 1378. There were no statistically significant differences in service costs after costs had been adjusted to take into account participant characteristics.	Supported living provides more positive consequences for service users than small or large group homes. The costs of each are comparable.
Emerson et al[a] (2000)	Community-based residential supports and residential campuses	Economic analysis	1997/1998 Great British Pounds	Cost per client per week and a range of quality of life and quality of care indicators	Accommodation costs: Dispersed housing; £1064 Residential campuses; £857. Non-accommodation costs: Dispersed housing; £154 Residential campuses; £95 There was a significant difference ($p<0.01$) in accommodations costs and total costs between dispersed housing and residential campuses.	Small community-based housing schemes were rated as significantly more beneficial in terms of quality of care and quality of life for service users. However, the total costs for dispersed housing schemes was significantly greater than those for residential campuses.
Emerson et al[b] (2000)	Dispersed, community housing schemes and village communities and residential campuses	Economic analysis	1997/1998 US Dollars	Cost per client per week and a range of quality of life indicators	Accommodation costs: Village communities; $986 Residential campuses; $1445 Dispersed housing schemes; $1400 Non-accommodation costs: Village communities; $228 Dispersed housing; $134 Residential campuses; $214	Dispersed housing schemes and village communities provided a significantly greater quality of care and quality of life for service users than residential campuses. However, costs were higher in dispersed housing schemes than residential campuses or village communities.

Table 2: Examples of treatments to be evaluated

Interventions	
Medication category	**Medication names**
Antipsychotics	Risperidone
	Haloperidol
Antidepressants	Fluoxetine
	Paroxetine
Mood Stabilisers	Lithium
	Sodium valproate
Opioid antagonists	Naltrexone
Anti-anxiety	Buspirone
	Diazepam
Non drug therapy	
Occupational therapy	
Psychological interventions	
Speech and language therapy	
Other management	

Figure 1: Patient pathways



References

Carers UK (2002). *Without us…? Calculating the value of carers' support*. Carers UK: London.

Comas-Herrera A, Knapp M, Beecham J, Pendaries C, Carthew R (2001). Benefit groups and resource groups for adults with intellectual disabilities in residential accommodation. *Journal of Applied Research in Intellectual Disabilities*, **14**:120-140.

Department of Health, Social Services and Public Safety (DHSSPS, November 2001). *Health and Social Well-being Survey, Informal Carers Report*.

Dockrell JE, Gaskell GD, Normand C, & Rehman H (1995). An economic analysis of the resettlement of people with mild learning disabilities and challenging behaviour. *Social Science & Medicine*, **40** (7): 859-901.

Drummond M (1995). The role of health economics in clinical evaluation. *Journal of Evaluation in Clinical Practice*, **1** (1): 71-75.

Emerson E, Robertson J, Gregory N, Hatton C, Kessissoglou S, Hallam A, Järbrink K, Knapp M, Netten A, & Noonan Walsh P (2001). Quality and costs of supported living residences and group homes in the United Kingdom. *American Journal on Mental Retardation*, **106** (5): 401-415.

Emerson E, Robertson J, Gregory N, Kessissoglou S, Hatton C, Hallam A, Knapp M, Järbrink K, Netten A, & Linehan C (2000a). The quality and costs of community-based residential supports and residential campuses for people with severe and complex disabilities. *Journal of Intellectual & Developmental Disability,* **25** (4): 263-279.

Emerson E, Robertson J, Gregory N, Hatton C, Kessissoglou S, Hallam A, Knapp M, Järbrink K, Noonan Walsh P, & Netten A (2000b). Quality and costs of community-based residential supports, village communities, and residential campuses in the United Kingdom. *American Journal on Mental Retard*ation, **105** (2): 81-102.

Felce D, Lowe K, Perry J, Baxter H, Jones E, Hallam A, Beecham J (1998): Service support to people in Wales with severe intellectual disability and the most severe challenging behaviours: process, outcomes and costs. *Journal of Intellectual Disability Research,* **42** (5): 390-408.

Hallam A & Knapp M (2004). The Economics of Intellectual Disability, in E Emerson, C Hatton, T Thompson & TR Parmenter (Eds) *The International Handbook of Applied Research in Intellectual Disabilities*. Chichester: John Wiley & Sons Ltd.

Hallam A, Knapp M, Järbrink K, Netten A, Emerson E, Robertson J, Gregory G, Hatton C, Kessissoglou S, & Durkan J (2002). Costs of village community, residential campus and dispersed housing provision for people with intellectual disability. *Journal of Intellectual Disability Research*, **46** (5): 394-404.

Henwood M (1998). *Ignored and Invisible: Carers' Experiences of the NHS*. Carers National Association (now Carers UK).

Hirst M (2004). Hearts and Minds: *The Health Effects of Caring*. Social Policy Research Unit, University of York and Carers UK.

Holzhausen E & Pearlman V (2000). *Caring on the Breadline- The Financial Implications of Caring*. Carers UK.

Knapp M, Comas-Herrera A, Astin J, Beecham J & Pendaries C (2005) Intellectual disability, challenging behaviour and cost in care accommodation: what are the links? *Health and Social Care in the Community,* **13** (4): 297-306.

National Statistics (October 2001). *Social Services Performance Assessment Framework Indicators, 2000-2001*. Department of Health and Government Statistical Service.

Robertson J, Emerson E, Pinkey L, Caesar E, Felce D, Meek A, Carr D, Lowe K, Knapp M, & Hallam A (2004). Quality and costs of community-based residential supports for people with mental retardation and challenging behavior. *American Journal on Mental Retardation*, **109** (4): 332-344.

Appendix 1: Glossary

Cost effectiveness analysis
The cost per unit of benefit of an intervention. In cost effectiveness analysis, the outcomes of different interventions are converted into health gains for which a cost can be associated, for example, cost per additional pressure ulcer prevented. Takes into account both the costs and outcomes of treatment.

Cost impact
The total cost to the person, the NHS, or to society.

Cost utility analysis
Measures the effect of treatment on individuals' length and quality of life. Results are usually reported in the form of cost per Quality Adjusted Life Years (QALYs). Takes into account both the costs and outcomes of treatments.

Economic evaluation
Comparative analysis of alternative courses or action in terms of both their costs and consequences.

Quality adjusted life expectancy
Life expectancy using quality adjusted life years rather than nominal years.

Quality adjusted life years (QALYs)
A measure of health outcome which assigns to each time period a weight, ranging from 0-1, corresponding to the health related quality of life during that period, where a weight of 1 corresponds to optimal health, and a weight of 0 corresponds to a health state judgement equivalent to death. These are then aggregated across time periods.