Service use and cost of mental disorder in older adults with intellectual disability

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Abstract

Aims

We report service use and costs of older people with intellectual disability (ID) and explore the influence of socio-demographic and illness-related determinants. Method

Accommodation charges; receipt of all health and personal care; physical as well as mental illness, dementia, sensory impairment and disability from a representative sample of older adults with ID aged 60 and older (n = 212) was analysed. Results

The average weekly cost per older person was £789 (£41 028 per year). Accommodation accounted for 74%. Overall costs were highest for those living in congregate settings; other settings had the highest cost for non-accommodation elements. Gender, ID severity, hearing impairment, physical disorder and mental illness had significant independent relationships with costs. Mental illness was associated with the largest additional weekly cost (£202).

Conclusions

Older adults with ID comprise about 0.15 - 0.25% of the population of England but consume up to 5% of the total personal care budget. Interventions to alleviate mental and physical illness may prove cost-effective in the longer-term.

Old age, mental illness and intellectual disability are amongst the main determinants of healthcare expenditure (Meerding, Bonneux, Polder, *et al*, 1998; Polder, Bonneux, Meerding, *et al*, 2002; Polder, Meerding, Bonneux, *et al*, 2002). In the general population psychiatric disorders can influence the cost of care for older adults, and both depression and dementia are significant predictors of high service costs (Livingston, Manela & Katona, 1997).The cost of caring for people with intellectual disability (ID) currently makes up a large proportion of health care spending in Western Europe (Polder, Meerding, Bonneux, *et al*, 2002) and may rise in line with the increasing numbers of people with ID now living to old age (Holland, 2000). This would be expected as the rates of mental illness and dementia in people with ID have been found to be higher than in the general population and the prevalence of affective disorders as well as dementia in people with ID, increases with age (Cooper, Smiley, Morrison, *et al*, 2007; Strydom, Livingston, King, *et al*, 2007).

There have been no published studies of costs of care of a representative sample of older people with ID. The present study reports service use patterns and costs for older people with ID, including accommodation, in- and outpatient care, as well as domiciliary and personal care. We hypothesised that dementia and other psychiatric disorders would be independently associated with increased care costs in this population and explored the influence of other possible socio-demographic and illness-related determinants.

Method

We undertook a survey of all adults with ID without Down Syndrome (DS) aged 60 and older living in five inner city and suburban London boroughs: Camden, Islington, Enfield, Harrow and Greenwich. The study is described in detail in earlier papers (Strydom, Hassiotis, King, *et al*, 2008; Strydom, Livingston, King, *et al*, 2007). Thames Valley Multi-centre Research Ethics Committee approved the study and it was agreed with the Research & Development offices of all participating National Health Service organisations.

Participants and consent procedures

All adults with ID aged 60 and older, who were currently resident in any of the five boroughs, were identified from:

1. Social services electronic databases and ID team health care records (current and past recipients of care who have been recorded at any time to have ID).

2. All local residential and day services providers (voluntary or government sector) for adults with ID.

Informed consent was obtained from participants with ID who had capacity but for those who lacked capacity we sought agreement from carers. We also gained consent from informants for their own participation in the survey. Informants were family members, social workers or care staff who had regular contact with the participants. If necessary, further informants or historical records were sought.

Severity of intellectual disability (ID)

Intellectual disability was defined according to ICD 10 criteria for mental retardation (MR) (WHO, 1992) as global developmental delay, IQ below 70 and impairment of social functioning. Those in whom the ID status was uncertain at screening underwent an assessment and were excluded if they did not meet these ICD 10 criteria. Each participant's severity of ID was rated to be mild, or more severe, according to their early and adult abilities (including IQ if available).

Physical health status

Informants provided us with current and past diagnoses, and clarification was sought from medical records if available. We grouped participants into those with one or more chronic health problem and those with none (i.e. health conditions which require long-term treatment such as cardiovascular disorders, including hypertension; lipid metabolism disorders, respiratory disease such as chronic obstructive airway disease, arthritic conditions, gastro-intestinal disorders such as peptic ulcers and chronic constipation, endocrine disorders such as diabetes, urinary or renal disorders such as chronic urinary tract infection and renal failure, haematological conditions such as anaemia, solid tumours, and neurological conditions such as epilepsy). Mobility was rated independently of other physical health problems from informants' responses to a measure of functional ability, based on the Activity of Daily Living Scale (ADLs) (Lawton & Brody, 1969). Normal mobility was defined as having no mobility problems requiring the use of a railing, cane, frame, wheelchair, or being bedridden. For the purposes of the analysis, participants were divided into those with and without mobility problems.

Hearing ability was assessed with the whispered voice test (Pirozzo, Papinczak & Glasziou, 2003). Participants using hearing aids were tested with their aids and hearing was rated as follows: No hearing impairment; Failed whisper test, but can hear speech of normal volume; Failed whisper test, and can only hear loud speech; Deaf or near deaf. The screening version of the Kay picture test (Kay, 1983) was used to screen for deficits in visual acuity. It was designed for 2- to 3-year old children, and has also successfully been used in adults with ID (Prasher, 1994; Woodhouse, Griffiths & Gedling, 2000). Participants using correction wore their glasses during testing and visual acuity was rated as follows: Normal; Impaired; Blind or almost blind (even after correction).

Mental health and dementia status

Participants were divided into those with and those without a current history (obtained from informants or health records) of one or more serious mental illnesses (including psychoses, affective disorders, anxiety disorders, severe behavioural problems and personality disorders which are currently being managed). We did not include a rating for Autistic Spectrum Disorders.

All participants were screened for cognitive or functional decline and memory function. Those who screened positive underwent a detailed assessment, and were diagnosed according to the ICD10, DSMIV and DC-LD diagnostic systems. For the purpose of this report, the participants were divided into those with and without dementia (according to whether they met any of the above diagnostic criteria).

Service use

All informants were interviewed using the Client Service Receipt Inventory (CSRI) adapted for use in intellectual disabilities (based on methodology described in Beecham & Knapp, 2001). This collects comprehensive data on a range of services including usual place of residence, accommodation charges, income and sources of income; receipt of all health, social care, and other services (day care, domiciliary care, respite care and nursing care, inpatient stays, primary and community care contact). Time spent caring by family, other unpaid carers and external providers and aids and adaptations used by study participants were also recorded. We collected data for the preceding three months, except for hospital services and aids and adaptations, which covered the previous six months.

Costs

All costs are expressed as weekly estimates.

The manager of the home supplied weekly accommodation charges for residential settings, or the care manager overseeing the placement, where information from the manager of the home was not available.

Costs of health and social care were estimated by combining health and social care resource utilisation data with unit costs (2005/06 levels). Unit costs were collected from a variety of national sources. Costs per contact with health and community professionals were taken from an annual national compendium (Curtis & Netten, 2006). Publicly available national reference costs were used to estimate the cost of outpatient attendances (Department of Health, 2006). Costs of informal care were estimated by combining the time spent in domiciliary and personal care by the national minimum hourly wage rate (Incomes Data Services, 2008). An estimate of the cost of nursing care by external provider to the service user was estimated by multiplying the nursing time spent by the unit cost of a district nurse (Curtis & Netten, 2006). Medication was recorded but not costed.

Missing data on day centre, hospital and community-based services were imputed using the median, while weekly accommodation charges were estimated using the median charge for individuals living in a similar setting.

The weekly cost of aids and adaptations was estimated using median annual costs divided by 52. For aids and adaptations not contained in this compendium costs were estimated by taking the price of the aid and discounting over 5 years at a discount rate of 3.5 % and dividing by 52.

Analysis

Ordinary least squares (OLS) analysis was used to examine the associations between baseline characteristics and total costs, modelled on analyses by Byford et al (2001). Bivariate analysis was used to investigate associations between each of baseline characteristics and the total costs of care, using simple linear regression. Associations between costs and continuous variables were conducted. All explanatory variables that had a bivariate association with costs were initially included in the model. Variables that did not have bivariate associations with costs were then included one at a time and were kept if they added significantly to the

model. The decision to retain or discard a variable was based on significance at the 10% level.

Results

We identified and contacted 281 potential participants. Of these, 24 (8.5%) were ineligible for the study. Of the remainder, 222 (86.4%) participated. The prevalence of eligible ID participants in the total population of all adults aged 60 and older was 0.15%. Participants' demographic details are given in table 1. One hundred and twenty-three (55.4%) participants were rated to have mild ID and 99 (44.6%) had moderate or more severe ID, and 41.9% had a diagnosis of mental disorder.

Most participants (89.6%) were dependent on state benefits for their income, but seventeen (10.4%) had income from private sources (such as pension, savings, or family support).

Tables 2 and 3 provide information about the cost of hospital and community services, daytime activities and direct care (if it was not included in the accommodation costs). Two hundred and fifteen (97%) participants were accessing some form of hospital or community service, the cost to agencies was £55 per week per participant (averaged to the whole sample). Daytime activities (e.g. day centre or social clubs) or respite were accessed by 108 (49%) of the sample, the average cost to service providers was £135 per week. Forty-six (21%) older adults had domiciliary and personal care provided externally (i.e. not as part of the accommodation package). The average cost was £17 per week.

Although 41.9% had a reported psychiatric disorder, just 20% (less than half of those with mental illness) were receiving input from psychiatrists, 12% had input from psychiatric nurses and only 4% had contact within the past 3 months with a psychologist.

Total cost of care per week is given in table 4. Accommodation costs consisted of 74% of the total. Daytime activities and hospital and community health care accounted for most of the remainder. Overall, the average weekly cost (including accommodation) per older person with ID was £789, or £41 038 per year (US \$63 233; €55 401 using purchasing power parity at 2006).

Table 5 provides a breakdown of total costs by accommodation type. The largest proportion of participants were living in residential type accommodation (n = 85; 38%)

followed by supported living schemes for adults with ID (n = 38; 17%); nursing homes (n = 30; 14%), and sheltered accommodation schemes (mostly schemes for older people, though some were similar schemes specifically for adults with ID) (n = 30; 14%). A small proportion of participants were living by themselves in council or privately owned flats, and with family members in private households. Overall costs (including accommodation) were highest for those living in respite units (though this was based on only three participants), followed by residential homes and nursing homes. Lowest costs were for those living in their own homes, sheltered accommodation, or private households. However, the latter group had the highest cost for non-accommodation elements (Table 5).

We examined demographic and clinical associations (age, sex, severity of intellectual disability, dementia, health problems, mobility problems, mental illness, hearing impairment and visual impairment) of total costs of care firstly by using linear regression analysis. Variables that had a bivariate association at 0.5% with costs (gender, level of disability, whether a hearing assessment was done, presence of health problems, presence of a mental health problem) were initially included in the model. The final model explained 21% of the observed cost variance, which included female gender, more severe ID, hearing impairment, presence of health problems and presence of mental health problems (table 6). On average, a diagnosis of mental illness was associated with an additional weekly cost of £202, moderate to severe ID incurred an increase in weekly cost of £201 over mild ID and health problems an additional £164 per week when adjusted for other explanatory variables.

Age, dementia, mobility problems and visual problems did not have a significant bivariate association with total costs in this sample of older adults with ID.

Discussion

To our knowledge this is the first detailed study of care costs and service use patterns for older adults with intellectual disability. Most of the older adults were living in supported settings, and accommodation costs accounted for 74% of the total costs. Overall, costs were therefore highest for those living in supported settings, while lowest costs were for those living independently. The latter tended to be associated with higher costs for non-accommodation elements. On average, the cost of hospital or other community services was relatively modest, at £55 per person per week, compared to the overall cost. However, a diagnosis of mental illness was an important association with higher costs, as was diagnosis of another health problem.

Several previous studies of cost of care associated with ID in the UK were of the deinstitutionalisation process. Moving people with ID into the community from hospitals during deinstitutionalisation was found to be associated with additional expenditure (Beecham, Knapp, McGilloway, *et al*, 1997; Dockrell, Gaskell, Normand, *et al*, 1995; Hallam, Beecham, Knapp, *et al*, 2006). We report for the first time the costs associated with mental illness and dementia in people with ID.

Limitations of this study

The study was of a large epidemiological sample – but it excluded adults with Down Syndrome (DS), who may be heavy users of services due to significant comorbidities such as physical disorders and dementia. However, few people with DS survive beyond the age of 60, and therefore the estimated costs should be representative of older adults with ID known to services. Although we set out to identify people all people with ID aged 60 and over, it is possible that we missed individuals not currently registered with community ID services. However, they are likely to be people with mild ID, who would be expected to incur relatively low ID associated service costs.

Dementia was diagnosed by screening and detailed assessment, but we relied on informant reports and clinical records for mental illness diagnoses. It is therefore possible that mental illness is under-represented in this study or that some people may have had previous affective illnesses but are currently well. Nevertheless, the rate of mental ill health in our study (excluding dementia) was comparable to that of a recent epidemiological survey of adults with ID (Cooper, Smiley, Morrison, *et al*, 2007). Although we made detailed assessment of costs and service use, it is possible that some elements relevant to overall costs were under- or over-estimated; e.g. fees were reported as average fees for the placement, rather than the actual fee for the particular individual, and certainly not the actual individual *cost* of care (which should be driven by an individual's needs for staffing support).

Costs associated with ID and aging

We did not demonstrate a relationship between age and cost in this sample of older adults with ID. There are several reasons for this. It is possible that due to the lifelong, complex disability associated with ID (which often includes mobility problems, problems with ADLs and health problems) the additional problems of ageing do not contribute significantly to the overall care and cost burden. Furthermore, those with most severe ID tend to die younger (Patja, Mölsä & livanainen, 2001), so that those that reach older age might be relatively healthy (Janicki, Davidson, Henderson, *et al*, 2002). There are several other inherent variations to consider; such as provider characteristics, motivation and particularly the pursuit of profits (Matosevic, Knapp & Le Grand, 2008); and there is the question of market structure, price-cost mark-up or subsidisation of charges and the purchasing power of local authorities and the NHS (Knapp, Hardy & Forder, 2001).

Studies of costs for older people with mental health needs in the general population have noted support costs rising with age, most likely due to increasing physical disability; however, studies that look at a wider age range – including people both above and below age 65 – tend to find that support costs for those with needs are generally lower for older people (Beecham, Knapp, Fernandez, *et al*, 2008).

Although cost estimates in our study cannot be directly compared with a younger age group, several other studies of costs associated with types of accommodation or various interventions such as person-centred planning have focused on younger adults with ID. For example, in a large survey of costs in care accommodation in England, higher costs and service use were associated with more severe intellectual disabilities and more challenging behaviour (Knapp, Comas-Herrera, Astin, *et al*, 2005). Another study of the comparative costs of supporting people in different settings found wide variations in cost between models of accommodation, individual organisations, settings and service users. In keeping with our results, multivariate analysis revealed that higher costs were associated with higher levels of ID and more severe challenging behaviour. Services for younger users, male users and smaller facilities were also associated with increased costs (Hallam, Knapp, Jarbrink, *et al*, 2002). Direct comparison of specific accommodation types have shown that semi-independent living may offer cost and quality of life benefits compared to fully staffed homes (Felce, Perry, Romeo, *et al*, 2008).

The costs per accommodation type in our study were similar to studies of predominantly younger adults (e.g. Hallam, Beecham, Knapp, *et al*, 2006), although the cost for supported living schemes in that study were lower than in our study. The needs of older adults with ID are higher than for younger adults due to multiple morbidity from aging, physical frailty and dementia (Cooper, 1997; Strydom, Hassiotis & Livingston, 2005), but despite this, at least for those placed in supported living schemes, the same or even less appear to be spent on them. While there may be several reasons for such differences, it is important to consider the possibility of

age discrimination, which may occur when older people are offered fewer opportunities and less intensive support or care than their younger peers.

Costs associated with dementia and mental illness in older adults with ID

Older people with ID were found to have higher rates of psychiatric morbidity than younger controls if dementia is included (Cooper, 1997). Although dementia was not a predictor of higher costs, mental illness emerged as the most important clinical predictor of costs. This contrasts with studies in the general population, which found that dementia was the most expensive psychiatric disorder in older adults in terms of formal services (Nelson et al, 2004), and was especially associated with increased social services costs. The average cost associated with late-onset dementia was £25472 per person (Knapp & Prince, 2007). However, having dementia was a negative predictor of health service use for those living in the community (Nelson, Livingston, Knapp, *et al*, 2002).

Dementia may not be associated with increased costs in the ID population for several reasons. The first is that when dementia occurs in disabled adults who are already being provided with supported accommodation and other personal social services, it is not associated with a significant increased use of resources. However, dementia often went undiagnosed and unmanaged (Strydom, Livingston, King, *et al*, 2007), which may also explain a relative lack of service use and costs.

Previous studies have suggested that mental illness, especially depression may also be a significant contributor to service costs in older adults in the general population (Livingston, Manela & Katona, 1997). Mental health problems occurred frequently in this sample of older adults with ID. Psychiatric disorders can be managed with medical and psychological interventions, which aim to reduce morbidity and to improve functional ability. Given the relative lack of health care input to people with ID who had mental health problems, and the relatively low expenditure on health care compared with accommodation and social care, there may be ample scope in this population to improve health care without making significant additional demands on overall costs. Indeed, mental health interventions may help to reduce the needs for intensive personal care and housing-related care and support costs in the long run. The potential impact on costs of improvements in mental health care of people with ID needs to be studied further in intervention studies.

Comparison with personal social services budget in England

During 2006/7, £20 billion was spent on all personal social services in England 2006-7, of which £3.3 billion was spent on adults aged under 65 with ID (National Statistics, 2008). This is in keeping with estimates from the Netherlands, which found nearly 10% of the care budget was spent on the care of people with ID (Polder, Meerding, Bonneux, *et al*, 2002). Using an overall administrative prevalence rate of 0.15% of the elderly population there are an estimated 15600 adults with ID aged 60 and older in England. Extrapolating the personal care costs (excluding hospital and community-based health care) from our study to this population, the cost of providing care to them is £595 million rising to nearly £1bn if the administrative prevalence rate of 0.25% suggested by Emerson and colleagues (Emerson & Hatton, 2004) is used. In other words, although older adults with ID still only make up a small proportion of the older population (0.15 – 0.25%), they currently consume up to 5% of the total care budget. Even small increases in the population of older adults with ID may therefore have considerable cost implications.

Implications

Older adults with ID are a growing population group, who consume a significant, disproportionate and increasing proportion of resources although perhaps less than their morbidity levels would suggest is equitable according to need. This study made use of a representative sample to provide data on demographics, service use and costs associated with their care, which can be used to predict future needs and to plan services. Although we focused on older adults with ID, these data may also give an indication of the services and costs required for younger adults with ID. We have demonstrated that mental illness, severity of disability and health problems are important predictors of costs; these characteristics should therefore influence resource allocation and service development at a local level.

It should be acknowledged that there might be unavoidable costs to services to provide care and support as people age; indeed, although we have demonstrated that older adults with ID use a significant proportion of care funding, there were also indications that service use and spending were less than expected given their needs. The frailty of old age may be underestimated, or subsumed into existing provision. Services and funders need to address these issues and ensure equal access to care and support, regardless of disability or age, in order to address age discrimination. It is also important to consider the needs of family carers - we have shown that for the

small number living with their families or on their own, non-accommodation costs (including health care and community services) are higher than for those living in communal settings. There are other added weekly costs to families, not to mention non-monetary costs not estimated in this study.

Nevertheless, there may also be considerable opportunities to improve care without large increases in overall spend, which could result in cost reduction in the longer term. This may be achieved though early identification of those with mental illness or behavioural problems, and offering them multi-disciplinary specialist assessment and support which could help to ensure placement in less restrictive and less costly environments, while reducing the risk to those with ID and mental illness or challenging behaviour and their carers. Such resources may require additional funding before cost benefits can be shown, but will be in keeping with the principles of the UK government white paper "Valuing People" which provides a strategy for the care of the adults with ID (Department of Health, 2001). The second Mansell report outlined how these principles need to be applied to services for people with ID and challenging behaviour or mental health needs (Department of Health, 2007). It emphasized the need to reduce costly placements (often out of area) by ensuring access to appropriate specialist support. Other ways in which services can improve care include creating suitable local accommodation options, education, work and day opportunities. Lastly, physical health care needs also need to be addressed. Health action planning and health facilitation (Department of Health, 2001), comprehensive health assessments (Lennox et al, 2007) and enhanced General Practitioner contracts will help to improve health care of adults with ID.

Policy and research developments

Health and social care policy is evolving at an accelerated pace in the UK and Europe. The current UK government policy is for resource funding the National Health Service through "payments by result (PbR)", which is set to be expanded (Department of Health, 2008). It may yet be applied to community mental health services. Other proposals include individual budgets and direct payments to users or carers (Department of Health, 2006). This is aimed at giving people more control and choice over their care, which may help to reduce age discrimination, but may require considerable administrative and accounting resources. The impact of such innovations on care costs remains to be seen, and will require further study.

Further research is required to define the service and cost impact of specific mental disorders and problem behaviours in this population. Further research effort is also required to study the cost-effectiveness of health and mental health interventions and new funding innovations in young and old adults with ID.

| Table 1: Demographic and health indicators | | | | | | |
|--|-----------|-----------|--|--|--|--|
| Age (years) | | | | | | |
| Mean (SD) | 69 | | | | | |
| Minimum | 60 | | | | | |
| Maximum | 94 | | | | | |
| | | | | | | |
| Ethnicity: number (%) | | | | | | |
| Asian/British Asian | 6 | (2.7%) | | | | |
| White | 215 | (96.8%) | | | | |
| Other | 1 | (.5%) | | | | |
| | | (10,0) | | | | |
| Males: number (%) | 117 | (52.7%) | | | | |
| | | () | | | | |
| Level of disability | | | | | | |
| Mild | 123 | (55.4%) | | | | |
| Moderate | 70 | (31.5%) | | | | |
| Severe | 29 | (13.1%) | | | | |
| 001010 | | (1011/0) | | | | |
| Mental health problem: number | | | | | | |
| (%) | 93 | (41.9%) | | | | |
| (70) | | | | | | |
| Dementia: number (%) | 29 | (13.1%) | | | | |
| | 20 | (10.170) | | | | |
| Health problem: number (%) | 183 | (82.4%) | | | | |
| ricalin problem. number (70) | 100 | (02.470) | | | | |
| Physical disability: number (%)* | 82 | (36.0%) | | | | |
| | 02 | (30.378) | | | | |
| Hearing impairment | | | | | | |
| No boaring impairment | 105 | (17 20/) | | | | |
| | 105 54 | (47.370) | | | | |
| | 04 | (24.3%) | | | | |
| Loud voice | 29 | (13.1%) | | | | |
| Near deat | 12 | (5.4%) | | | | |
| N/2 1 · · · | | | | | | |
| visual impairment | 40 | (04.63()) | | | | |
| No impairment | 48 | (21.6%) | | | | |
| Impaired | 124 | (55.9%) | | | | |
| Almost blind | 12 | (5.4%) | | | | |

Table 1. Demographic and health indicators

Table 2: Hospital and community-based service costs

| | Full sample | |
|-------------------------------|---------------------|---------------------------------|
| | (n=222) | |
| | Number Using (%) | Average weekly cost (£) (SD) |
| Hospital based services | | |
| Inpatient services | 47(21%) | 20.9 (92.4) |
| Outpatient services | 87(39%) | 5.2 (12.2) |
| Accident and emergency | 22(10%) | 0.9 (5.3) |
| Total hospital based services | 114(51%) | 27.1 (94.3) |
| | | |
| Community based services | | |
| General practitioner | 160 (72%) | 2.4(3.7) |
| Psychiatrist | 45 (20%) | 1.7(6.0) |
| Clinical psychologist | 9 (4%) | 0.2(1.3) |
| Community psychiatric nurse | 27 (12%) | 0.8(3.9) |
| Community nurse | 47 (21%) | 1.5(12.2) |
| Speech and language therapist | 7 (3%) | 0.2(1.6) |
| Physiotherapist | 13 (6%) | 0.5(2.9) |
| Chiropodist | 137 (62%) | 1.1(1.23) |
| Occupational therapist | 18 (8%) | 1.0(7.7) |
| Alternative therapist | 21 (9%) | 2.4(9.3) |
| Art/drama therapist | 12 (5%) | 1.4(6.6) |
| Social worker | 63 (28%) | 0.8(2.3) |
| Counsellor | 18 (8%) | 1.0(4.6) |
| Dentist | 90 (41%) | 2.5(4.9) |
| Dietician | 13 (6%) | 0.5(3.4) |

| Family support worker | 14 (6%) | 1.8(7.7) |
|--|-----------|--------------|
| Voluntary worker | 21 (9%) | 1.7(7.4) |
| Befriender | 17 (8%) | 2.6(21.1) |
| Meals on wheels | 7 (3%) | 4.1(29.8) |
| Total community based services | 210 (95%) | 28.1 (45.9) |
| | | |
| Total service based costs (hospital and community based service) | 215 (97%) | 55.2 (107.2) |

Table 3: daytime activity and direct care costs

| | Full sample | | | | | | | |
|---------------------------------------|------------------|------------------------------|--|--|--|--|--|--|
| | (n=222) | | | | | | | |
| | No. Using (%) | Average weekly cost (£) (SD) | | | | | | |
| Daycentre | 104 (47%) | 125.6 (156.2) | | | | | | |
| Social club | 8 (4%) | 3.3 (21.7) | | | | | | |
| Respite care | 6 (3%) | 5.9 (41.3) | | | | | | |
| Total daytime activity costs per week | 108 (49%) | 134.8 (168.2) | | | | | | |

Full sample

A. Day time and respite activities cost per week

B. Cost of care provided by family and external providers per week

| | (n=222) | | | | |
|--|---------------|------------------------------|--|--|--|
| | No. Using (%) | Average weekly cost (£) (SD) | | | |
| Care by family | | | | | |
| Domiciliary | 14 (6%) | 2.1 (12.9) | | | |
| Personal care | 9 (4%) | 1.3 (10.8) | | | |
| Total cost of care by family | 16 (7%) | 3.4 (23.1) | | | |
| Care provided by external providers | | | | | |
| Domiciliary | 14 (6%) | 5.1 (19.9) | | | |
| Personal care | 24 (11%) | 6.1 (23.3) | | | |
| Nursing care | 3 (1%) | 2.4 (23.8) | | | |
| Total cost of care by external providers | 36 (16%) | 13.6 (45.7) | | | |
| Total costs of care per week | 46 (21%) | 17.0 (54.6) | | | |

Table 4: Total cost of care per week

| | Full sample | Mental health problem* | Without mental health |
|---|------------------------------|------------------------|-----------------------|
| | (n=222) | (n=93) | problem |
| | | | (n=129) |
| | Average weekly cost (£) (SD) | | |
| | | | |
| Accommodation | 582 (371) | 673 (341) | 516 (378) |
| Aids and adaptations | 0.3 (1) | 0.3 (1) | 0.2 (1) |
| Hospital and community based care | 55 (107) | 69 (144) | 45 (68) |
| Daytime activities | 135 (168) | 144 (171) | 129 (166) |
| Care by family | 3 (23) | 5 (33) | 3 (12) |
| Care by external providers | 14 (46) | 12 (47) | 15 (45) |
| Total costs of care per week <i>including</i> accommodation | 789 (423) | 903 (347) | 708 (413) |
| Total cost of care per week <i>excluding</i> accommodation | 207 (202) | 230 (234) | 192 (174) |

*Includes behavioural problems, but not dementia

Table 5: Cost of care per week by accommodation type

| | Average weekly cost (£) | | | | | | | | | |
|---|--------------------------------|--|---|----------------------------|---------------------------|--------------------------------|-------------------|----------------------------------|--------------------------|-------------------------------|
| | Residenti al care (n=85) | Supported living schemes (n=38) | Shared Private households (n=14) | Living on own (n=22) | Nursing home (n=30) | Sheltered schemes (n=30) | Hospital (n=4) | Adult foster care (n=3) | Respite unit (n=3) | Short stay hostel (n=1) |
| Accommodation | 779 | 661 | 0 | 0 | 779 | 347 | 574 | 360 | 1078 | 246 |
| Aids and adaptations | 0.33 | 0.35 | 0.01 | 0.01 | 0.40 | 0.14 | 0 | 0 | 0 | 0.46 |
| Hospital and community based care | 38 | 25 | 253 | 77 | 46 | 101 | 299 | 23 | 77 | 0 |
| Daytime activities | 165 | 137 | 312 | 66 | 84 | 93 | 0 | 300 | 39 | 240 |
| Care by family | 0 | 8 | 24 | 4 | 0 | 2 | 0 | 12 | 0 | 0 |
| Care by external providers | 3 | 12 | 59 | 55 | 0 | 33 | 0 | 0 | 0 | 0 |
| Total costs of care per week <i>including</i> accommodation | 985 | 844 | 648 | 203 | 910 | 576 | 873 | 695 | 1193 | 486 |
| Total cost of care per week <i>excluding</i> accommodation | 206 | 183 | 648 | 203 | 131 | 229 | 299 | 335 | 115 | 240 |

Table 6. Predictors of total cost of care

| | β | Standard error | P-value |
|--|----------------------------|----------------------|---------|
| | | | |
| Constant | 317.97 | 92.72 | .001 |
| Gender: relative to male | 84.69 | 51.98 | .105 |
| Level of learning disability: relative to mild learning disability | 200.98 | 42.75 | .000 |
| Hearing impairment: relative to no impairment | 25.05 | 28.61 | .382 |
| Health problems: relative to no health problems | 163.66 | 68.07 | .017 |
| Mental health problems: relative to no mental health problems | 201.82 | 51.50 | .000 |
| Goodness of fit statistics | R ² = 0.21; adj | usted $R^{2} = 0.19$ | |
| | F(5,193) = 4.0 | 04 (p = .00) | |

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