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### 8.1.1 Community care package for older people: very low cost

The care package costs described in this schema are an example of a case where the costs to the public purse on health and social care support are in the lowest decile in a 2005 home care sample of 365 cases.<sup>1</sup> In this sample, which had 35 per cent of 'intensive' cases with 10 or more home care hours per week compared with 26 per cent in England as a whole, 10 per cent of cases incurred gross public community care costs of less than £49 per week. Package costs exclude the costs of hospital and any use of care homes for respite care. Social work/care management costs were included only where visits from a social worker during the previous three months were reported by the individual. GP visits were not collected so estimates based on national data have been included. All costs have been uprated with the appropriate inflators.

<b>Type of case</b>			
Mrs A was an 83 year old widow who lived alone in sheltered accommodation (excluding housing support) but received help from two people, with most help coming from another family member.			
<b>Functional ability</b>			
Mrs A. had problems with three activities of daily living: stairs, getting around outside, and bathing. Her problems stemmed from a previous stroke.			
Services	Average weekly cost	Level of service	Description
<b>Social care</b>			
Home care	£21.40		One hour per week of local authority-organised home care.
Meals on Wheels	£25.00		Based on the average gross weekly expenditure on meals for older people receiving them. Taken from PSS EX1 2008/09, the average cost per meal on wheels was £6.00 for the Local Authority and £4.00 for the independent sector. Costs have been uprated using the PSS Pay & Prices Inflator.
<b>Health care</b>			
GP	£7.94	11.7 minutes	Surgery visits estimated at once every four weeks based on the General Practitioner Workload Survey, July 2007. <sup>2</sup>
Accommodation	£169		Based on the weekly cost of sheltered accommodation (see 1.9, page 57).
Living expenses	£149		Taken from the Family Expenditure Survey (2009), uprated to 2009/2010 price levels). <sup>3</sup> Based on one retired adult household, mainly dependent on state pensions.
<b>Total weekly cost of health and social care package</b>	£55 £372		Excludes accommodation and living expenses. All costs.

1 Darton, R., Forder, J., Bebbington, A., Netten, A., Towers, A-M. & Williams, J. (2006) Analysis to support the development of the Relative Needs Formula for Older People, PSSRU Discussion Paper 2265/3, Personal Social Services Research Unit, University of Kent, Canterbury.

2 The Information Centre (2007) *2006/07 UK General Practice Workload Survey*, Primary Care Statistics, The Information Centre, Leeds.

3 Office for National Statistics (2009) *Family Spending 2009 Edition*, Office for National Statistics, London, available at [http://www.statistics.gov.uk/downloads/theme\\_social/Family-Spending-2008/FamilySpending2009.pdf](http://www.statistics.gov.uk/downloads/theme_social/Family-Spending-2008/FamilySpending2009.pdf)

## 8.1.2 Community care package for older people: low cost

The care package costs described in this schema are an example of a case where the costs to the public purse on health and social care support are in the bottom quartile in a 2005 home care sample of 365 cases.<sup>1</sup> In this sample, which had 35 per cent of 'intensive' cases with 10 or more home care hours per week compared with 26 per cent in England as a whole, 25 per cent of cases incurred gross public community care costs of less than £92 per week. Package costs exclude the costs of hospital and any use of care homes for respite care. Social work/care management costs were included only where visits from a social worker during the previous three months were reported by the individual. GP visits were not collected so estimates based on national data have been included. All costs have been uprated using the appropriate inflators.

<b>Type of case</b> Mrs B. was a 79 year old widow who lived alone but received help from two people, most help being provided by a family member.			
<b>Functional ability</b> Mrs B. had problems with three activities of daily living: stairs, getting around outside and bathing. Her problems stemmed from arthritic conditions and cardiovascular disease.			
Services	Average weekly cost	Level of service	Description
<b>Social care</b>			
Home care	£86	4 hours per week	Based on 4 hours of local authority-organised home care.
Private home care	£40	3 hours per week	Based on 3 hours of independently provided home care.
<b>Health care</b>			
Community nurse	£6.80	11.7 minutes	Community nurse visits once a month. Home visits estimated at once every four weeks based on the General Practitioner Workload Survey, July 2007. <sup>2</sup>
GP	£7.90		
Accommodation	£75		The national average weekly gross rent for a two bedroom house in the social housing sector including £5.57 service charge. <sup>3</sup>
Living expenses	£149		Taken from the Family Expenditure Survey (2009), uprated to 2009/2010 price levels). <sup>4</sup> Based on one retired person household, mainly dependent on state pensions.
<b>Total weekly cost of health and social care package</b>	£141 £365		Excludes accommodation and living expenses and independently provided home care. All costs.

1 Darton, R., Forder, J., Bebbington, A., Netten, A., Towers, A-M. & Williams, J. (2006) Analysis to support the development of the Relative Needs Formula for Older People, PSSRU Discussion Paper 2265/3, Personal Social Services Research Unit, University of Kent, Canterbury.

2 The Information Centre (2007) *2006/07 UK General Practice Workload Survey*, Primary Care Statistics, The Information Centre, Leeds.

3 Dataspring (2009) *Guide to Local Rents 2009 Part II: Social Landlord Rents, 2005-09*, The Cambridge Centre for Housing and Planning Research, University of Cambridge, [www.dataspring.org.uk](http://www.dataspring.org.uk).

4 Office for National Statistics (2007) *Family Spending 2007 Edition*, Office for National Statistics, London, available at [http://www.statistics.gov.uk/downloads/theme\\_social/Family-Spending-2008/FamilySpending2009.pdf](http://www.statistics.gov.uk/downloads/theme_social/Family-Spending-2008/FamilySpending2009.pdf)

### 8.1.3 Community care package for older people: median cost

The care package costs described in this schema illustrate the median public expenditure costs of £166 per week on health and social care support in a 2005 home care sample of 365 cases.<sup>1</sup> In this sample there were 35 per cent of 'intensive' cases with 10 or more home care hours per week compared with 26 per cent in England as a whole. Package costs exclude the costs of hospital and any use of care homes for respite care. Social work/care management costs were included only where visits from a social worker during the previous three months were reported by the individual. GP visits were not collected so estimates based on national data have been included. All costs have been uprated using the appropriate inflators.

<b>Type of case</b> Mrs D. was an 80 year old widow living with two other relatives.			
<b>Functional ability</b> Mrs D. had problems with four activities of daily living: stairs, getting around outside, dressing and bathing.			
<b>Services</b>	<b>Average weekly cost</b>	<b>Level of service</b>	<b>Description</b>
<b>Social care</b> Home care	£214	10 hours per week	Based on the cost of local authority-organised home care.
<b>Health care</b> GP	£7.90	11.7 minutes	Visits estimated at once every four weeks based on the General Practitioner Workload Survey, July 2007. <sup>2</sup>
Accommodation	£74		Shared three bedroom house/bungalow with two other relatives. Privately rented. Based on the average (private) rental income in England in 2009 and adjusted to take account of shared situation. <sup>3</sup> Uprated using the retail price index.
Living expenses	£149		Living expenses taken from the Family Expenditure Survey (2009), uprated to 2009/2010 price levels. <sup>4</sup> Based on one man retired household mainly dependent on state pensions.
<b>Total weekly cost of health and social care package</b>	£223 £445		Excludes accommodation and living expenses. Includes all costs.

1 Darton, R., Forder, J., Bebbington, A., Netten, A., Towers, A-M. & Williams, J. (2006) Analysis to support the development of the Relative Needs Formula for Older People, PSSRU Discussion Paper 2265/3, Personal Social Services Research Unit, University of Kent.

2 The Information Centre (2007) 2006/07 UK General Practice Workload Survey, Primary Care Statistics, The Information Centre, Leeds.

3 Rentright, Average price for England, [http://www.rentright.co.uk/country/england/3\\_rrpi.aspx](http://www.rentright.co.uk/country/england/3_rrpi.aspx), Accessed September 28 2009.

4 Office for National Statistics (2009) *Family Spending 2008 Edition*, Office for National Statistics, London, available at [http://www.statistics.gov.uk/downloads/theme\\_social/Family-Spending-2008/FamilySpending2009.pdf](http://www.statistics.gov.uk/downloads/theme_social/Family-Spending-2008/FamilySpending2009.pdf)

### 8.1.4 Community care package for older people: high cost

The care package costs described in this schema are an example of a case where the costs to the public purse on health and social care support are in the top quartile in a 2005 home care sample of 365 cases.<sup>1</sup> In this sample, which had 35 per cent of 'intensive' cases with 10 or more home care hours per week compared with 26 per cent in England as a whole, 25 per cent of cases incurred gross public community care costs of over £275 per week. Package costs exclude the costs of hospital and any use of care homes for respite care. Social work/care management costs were included only where visits from a social worker during the previous three months were reported by the individual. GP visits were not collected so estimates based on national data have been included. All costs have been uprated using the appropriate inflators.

<b>Type of case</b>			
Mr D. was a 79 year old widower who owned his own home and lived with two other friends. One of these friends provided him with help.			
<b>Functional ability</b>			
Mr D. had problems with seven activities of daily living: stairs, getting around outside and inside the house, using the toilet, transferring between chair and bed, dressing and bathing. His problems stemmed from arthritic conditions and a previous stroke.			
<b>Services</b>	<b>Average weekly cost</b>	<b>Level of service</b>	<b>Description</b>
<b>Social care</b>			
Home care	£214		10 hours per week. Based on local authority-organised home care.
Day care	£36		Attended a day centre about once a week.
Private home care	£318		Based on PSS EX1 2008/09 uprated using the PSS Pay & Prices Inflater. Cost of 24 hours of independently provided home care.
<b>Health care</b>			
Community nurse	£27	11.7 minutes	Once a week visit from a community nurse.
OT	£23		A couple of visits from the OT during the previous month.
GP	£7.90		Visits estimated at once every four weeks based on the General Practitioner Workload Survey, July 2007. <sup>2</sup>
Accommodation	£77		Owner occupied two bedroom house shared with two others. Based on the annuitised value of a detached house and shared between three people. Taken from the Halifax Price Index, 2nd quarter 2010.
Living expenses	£202		Living expenses taken from the Family Expenditure Survey (2009). <sup>3</sup> Based on one man and one woman retired household, not mainly dependent on state pensions.
<b>Total weekly cost of health and social care package</b>	£626 £905		Excludes accommodation and living expenses and privately purchased home care. Total package costs.

1 Darton, R., Forder, J., Bebbington, A., Netten, A., Towers, A-M. & Williams, J. (2006) Analysis to support the development of the Relative Needs Formula for Older People, PSSRU Discussion Paper 2265/3, Personal Social Services Research Unit, University of Kent, Canterbury.

2 The Information Centre (2007) *2006/07 UK General Practice Workload Survey, Primary Care Statistics*, The Information Centre, Leeds.

3 Office for National Statistics (2009) *Family Spending 2009 Edition*, Office for National Statistics, London, available at [http://www.statistics.gov.uk/downloads/theme\\_social/Family-Spending-2008/FamilySpending2009.pdf](http://www.statistics.gov.uk/downloads/theme_social/Family-Spending-2008/FamilySpending2009.pdf)

### 8.1.5 Community care package for older people: very high cost

The care package costs described in this schema are an example of a case where the costs to the public purse on health and social care support are in the top decile in a 2005 home care sample of 365 cases.<sup>1</sup> In this sample, which had 35 per cent of 'intensive' cases with 10 or more home care hours per week compared with 26 per cent in England as a whole, 10 per cent of cases incurred gross public community care costs of over £380 per week. Package costs exclude the costs of hospital and any use of care homes for respite care. Social work/care management costs were included only where visits from a social worker during the previous three months were reported by the individual. GP visits were not collected so estimates based on national data have been included. All costs have been uprated using the appropriate inflators.

<b>Type of case</b>			
Mrs E was a 82 year old woman who was married and lived with her husband and another relative in her own home. Her husband provided most support.			
<b>Functional ability</b>			
Mrs E suffered from dementia and needed help with nine activities of daily living: stairs, getting around outside and inside the house, using the toilet, transferring between chair and bed, dressing, bathing, washing and feeding.			
<b>Services</b>	<b>Average weekly costs</b>	<b>Level of service</b>	<b>Description</b>
<b>Social services</b>			
Home care	£642		30 hours per week of local authority-organised home care.
<b>Health care</b>			
Community nurse	£27	11.7 minutes	Once a week visit from a community nurse. Visits estimated at once every four weeks based on the General Practitioner Workload Survey, July 2007. <sup>2</sup>
GP	£7.90		
Accommodation	£39		Owner occupied two bedroom house shared with her husband and another relative. Based on the annuitised value of a terraced house and shared between three people. Taken from the Halifax Price Index, 2nd quarter 2010.
Living expenses	£202		Living expenses taken from the Family Expenditure Survey (2009). <sup>3</sup> Based on one man retired household, not mainly dependent on state pension.
<b>Total weekly cost of health and social care package</b>	£677 £918		Excludes accommodation and living expenses. All costs.

1 Darton, R., Forder, J., Bebbington, A., Netten, A., Towers, A-M. & Williams, J. (2006) Analysis to support the development of the Relative Needs Formula for Older People, PSSRU Discussion Paper 2265/3, Personal Social Services Research Unit, University of Kent, Canterbury.

2 The Information Centre (2007) *2006/07 UK General Practice Workload Survey, Primary Care Statistics*, The Information Centre, Leeds.

3 Office for National Statistics (2007) *Family Spending 2007 Edition*, Office for National Statistics, London, available at [http://www.statistics.gov.uk/downloads/theme\\_social/Family-Spending-2008/FamilySpending2009.pdf](http://www.statistics.gov.uk/downloads/theme_social/Family-Spending-2008/FamilySpending2009.pdf)

## 8.2 The cost of autism

There is growing evidence of the economic burden of autism spectrum disorders (ASD). Autism has life-time consequences with a range of impacts on the health, economic well-being, social integration and quality of life of individuals with the disorder, their families and potentially the rest of society. Many of those impacts can be expressed as economic costs.

Interventions and services currently used to treat or support children and adults with ASD include services provided by medical practitioners, nurses, dieticians, psychologists, speech and language therapists, teachers and various providers of complementary and alternative medicine, such as music therapy, aromatherapy, homeopathic remedies, naturopathic remedies, manipulative body therapies, and spiritual healing. These treatments, services and supports all impose costs either to the state or to a charity or to the families of people with ASD who have to pay for them out of their own pockets.

Here we present cost information taken from two research studies, the first of which focuses on pre-school children and provides the service and wider societal costs in the UK (Barrett et al., 2010)<sup>1</sup>. It looked at the services received by 152 pre-school children with autism, reported family out of pocket expenses and productivity losses and explored the relationship between family characteristics and costs.

Service use data were collected using a modified version of the Child and Adolescent Service Use Schedule (CA-SUS), which was developed by the authors in previous studies and adapted for the purpose of this study on the basis of expert opinion and pilot testing during the start up phase of the study. This was used to collect data on the use of specialist accommodation such as foster and respite care, education or day care facilities attended, all medication prescribed for the individual child, all hospital contacts, and all community health, education and social care services, including non-statutory provision. Education services provided were not recorded in order to avoid double counting the costs of those services included in the overall cost of the education facility and because parents may not always be aware of all services received by their child, particularly specialist facilities. In addition, parents were asked to report details of time off work due to their child's illness and expenditure on any specialist equipment or other extraordinary costs, such as home adaptations, conference or training attendance and overseas travel that were a direct result of their child's autism. Information from this study is found in 8.2.1.

The second study provides the annual costs for children (from the ages of 3-17) and adults with low-functioning and high functioning ASD (i.e. with and without an intellectual disability). The research carried out by Knapp et al. (2007; 2009)<sup>2,3</sup> estimated the full costs of autism spectrum disorders (ASDs) in the United Kingdom using data on 146 children and 91 adults. In the sample of children with autism, ages ranged from 3 to 17, with a mean of 10.28 years (standard deviation 3.173) and a median age of 10. Data was taken from a variety of sources, including: national surveys, published research, previous studies by the Institute of Psychiatry and expert advice. The purpose of the study was to examine the service, family and other economic consequences of autism in the UK, both for children and adults, with ASDs, with and without an intellectual disability. Tables presenting costs from this study are 8.2.2 to 8.2.4.

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1 Barrett, B., Byford, S., Sharac, J., Hudry, K., Leadbitter, K., Temple, K., Aldred, C., Slonims, V., Green, J. & the PACT Consortium (2010) *Service and Wider Societal Costs of Pre-School Children with Autism in the UK*, King's College London, University College London, University of Manchester, Newcastle University, Stockport Primary Care Trust, Guy's Hospital London, and the PACT Consortium, UK (not publicly available).

2 Knapp, M., Romeo, R. & Beecham, J. (2007) *The Economic Consequences of Autism in the UK*, Report to the Foundation for People with Learning Disabilities, London.

3 Knapp, M., Romeo, R. & Beecham, J. (2009) Economic cost of autism in the UK, *Autism*, 13, 3, May, 317-336.

## 8.2.1 Children with autism (pre-school)

Information for this schema has been taken from Barrett et al. (2010)<sup>1</sup>. All costs presented were for 2006/2007 and have therefore been updated to 2009/2010 using the appropriate inflators.

This table reports the service and wider societal costs for the six months prior to interview for pre-school children with autism. The mean total service costs were £2,781, equivalent to £463 per month and over £5,500 per year. Almost half the costs (45 per cent) were for education and childcare, 41 per cent were for community health and social services and 12 per cent for hospital services. As total costs varied substantially between the children in the study (range £338 to £7,145 over six months), box 1 below presents case studies of low and high cost cases.

On average, families spent an additional £242 as a result of their child's illness over the six months prior to interview (range 0 to £3,574). Fifty-one per cent of families reported taking some time off work due to their child's illness over the six months, associated with productivity losses of £293 per family. Total costs including all services, family costs and productivity losses were estimated over £3,000 over six months, equivalent to more than £500 per month.

### Total costs per child for the six months prior to interview (£, n=152)

	Mean £	SD	% of total service cost	% of total cost
Accommodation	17	225	0.62	0.52
Hospital based health services	327	479	11.66	9.76
Community health and social services	1,159	971	41.30	34.58
Medication	17	85	0.62	0.52
Voluntary sector services	32	87	1.16	0.97
Education and child care	1,229	879	44.63	37.37
<b>Total service costs</b>	<b>2,781</b>	1,344	<b>100.00</b>	<b>83.72</b>
Out-of-pocket expenses	242	537		7.36
Productivity losses	293	671		8.92
<b>Total costs</b>	<b>3,316</b>	1,796		<b>100.00</b>

### Box 1 Case studies of low and high cost cases

#### High cost — £6,576 over six months

Child H attends a mainstream nursery part-time and a specialist playgroup one day a week. He spent three nights in hospital following a grommet operation and had two outpatient appointments with the ear, nose and throat specialist before and after the operation. Child H had monthly visits to his GP, regular contact with the practice nurse and his health visitor, and weekly contacts with a speech and language therapist at the local health centre. In addition, he had contact with a community paediatrician and a portage worker.

#### Low cost — £338 over six months

Child I does not attend any formal education or childcare, spending all his time at home with his mother. He had one visit to a paediatrician at the local hospital, but did not have any other hospital contacts or use any services in the community.

1 Barrett, B., Byford, S., Sharac, J., Hudry, K., Leadbitter, K., Temple, K., Aldred, C., Slonims, V., Green, J. & the PACT Consortium (2010) *Service and Wider Societal Costs of Pre-School Children with Autism in the UK*, King's College London, University College London, University of Manchester, Newcastle University, Stockport Primary Care Trust, Guy's Hospital London, and the PACT Consortium, UK (not publicly available).

## 8.2.2 Children with low-functioning autism (ages 0 – 17)

The research carried out by Knapp et al. (2007; 2009)<sup>1,2</sup> estimated the full costs of autism spectrum disorders (ASDs) in the United Kingdom using data on 146 children and 91 adults.

The table below summarises the average cost per child with low-functioning ASD, whether living with their families or living in a residential or foster care placement. Costs are organised under a number of different service and support headings. Family expenses were also included and where appropriate, costs were imputed for the lost employment of parents. The table distinguishes children in the three different age groups that were used. The annual costs for children with low-functioning ASD who are living in residential or foster placements are estimated to be £17,693 (if aged 0-3), £44,335 (aged 4-11) and £68,325 (aged 12-17). For the two older age groups the largest contributors to these totals are the care placements themselves, and special education. The authors noted that given the availability of data, residential special school costs may have been underestimated.

Costs for children with low-functioning ASD who live with families are much lower: £4,744 (if aged 0-3), £30,449 (aged 4-11) and £44,221 (aged 12-17). For the two older age groups the largest contributors to these totals are special education, and health and social care services (including hospital and respite care).

### Average annual cost per child with low-functioning ASD (£)

	Living in residential or foster care placement			Living in private households with family		
	Ages 0-3	Ages 4-11	Ages 12-17	Ages 0-3	Ages 4-11	Ages 12-17
Residential/foster care placement	17,044	24,544	34,884	-	-	-
Hospital services	-	942	1,734	-	942	1,734
Other health and social services	639	7,548	437	639	7,548	437
Respite care	-	-	-	-	3,088	4,025
Special education	-	9,988	30,165	-	9,988	30,165
Education support	-	1,294	1,089	-	1,294	1,089
Treatments	-	20	16	-	20	16
Help from voluntary organisations	-	-	-	-	921	105
Benefits	-	-	-	4,105	4,370	4,370
Lost employment (parents)	-	-	-	-	2,279	2,279
<b>Total annual cost (excluding benefits)</b>	17,683	44,335	68,325	639	26,079	39,851
<b>Total annual cost (including benefits)</b>	17,693	44,335	68,325	4,744	30,449	44,221

Note: Expenditure on social security/welfare benefits could partly double-count the costs of lost employment for parents, which is why two totals are provided above.

1 Knapp, M., Romeo, R. & Beecham, J. (2007) *The Economic Consequences of Autism in the UK*, Report to the Foundation for People with Learning Disabilities, London.

2 Knapp, M., Romeo, R. & Beecham, J. (2009) Economic cost of autism in the UK, *Autism*, 13, 3, May, 317-336.

### 8.2.3 Children with high-functioning autism (ages 0 – 17)

The research carried out by Knapp et al. (2007; 2009)<sup>1,2</sup> estimated the full costs of autism spectrum disorders (ASDs) in the United Kingdom using data on 146 children and 91 adults.

As in schema 8.6.2, the table below distinguishes costs under a number of different service and support headings. The study suggests that all children with high-functioning ASD were assumed to live with their parents. Average costs range from £1,839 to £23,555 per annum.

#### Average annual cost per child with high functioning ASD (£)

	Living in private household with family		
	Ages 0-3	Ages 4-11	Ages 12-17
Hospital services	-	849	849
Other health and social services	1,326	1,326	1,326
Respite care	-	7,113	7,113
Special education	-	12,761	12,761
Education support	-	595	595
Treatments	-	162	162
Help from voluntary organisations	-	-	-
Benefits	512	512	512
Lost employment (parents)	-	236	236
<b>Total annual cost (excluding benefits)</b>	1,326	23,042	23,042
<b>Total annual cost (including benefits)</b>	1,839	23,555	23,555

Note: Expenditure on social security/welfare benefits could partly double-count the costs of lost employment for parents, which is why two totals are provided above.

1 Knapp, M., Romeo, R. & Beecham, J. (2007) *The Economic Consequences of Autism in the UK*, Report to the Foundation for People with Learning Disabilities, London.

2 Knapp, M., Romeo, R. and Beecham, J. (2009) Economic cost of autism in the UK, *Autism*, 13, 3, May, 317-336.

## 8.2.4 Adults with autism

The research carried out by Knapp et al. (2007; 2009)<sup>1,2</sup> estimated the full costs of autism spectrum disorders (ASDs) in the United Kingdom using data on 146 children and 91 adults. The estimated annual costs for adults with high-and low-functioning ASD are presented below. Imputed costs for lost employment are included for both the individuals with ASD and for parents, where these are appropriate. Costs are arranged by place of residence.

For an adult with high-functioning ASD, it is estimated that the annual cost of living in a private household (with or without family) is £36,460. A sizeable part of this (£21,617) is the imputed cost of lost employment for the individual with ASD (and hence also lost productivity to the economy). Part of that (not separately identified here) would be lost tax revenue to the Exchequer.

Costs for high-functioning adults in supported living settings or care homes are much higher (£93,230 and £96,193 per annum respectively) and the proportion attributable to lost employment is lower. The largest cost element in each case is for accommodation, and includes the costs of staff employed in those settings or supporting the residents.

For low-functioning adults, the mean annual costs (excluding benefits but including lost employment) rise with increased support in the accommodation for those living in private households from £47,014 to £107,934 for those in hospital care.

### Average annual cost per adult with ASD (£)

	Adults with high-functioning ASD			Adults with low-functioning ASD			
	Private household	Supporting People	Residential care	Private household	Supporting People	Residential care	Hospital
Accommodation	1,626	64,486	67,449	-	64,486	67,448	-
Hospital services	849	849	849	95	164	37	82,468
Other health and social services	531	531	531	773	511	633	-
Respite care	-	-	-	1,678	-	-	-
Day services	2,432	2,432	2,432	4,099	3,958	906	-
Adult education	3,153	3,153	3,153	1,568	930	3,623	-
Employment support	-	-	-	551	1,194	-	-
Treatments	162	162	162	68	68	68	-
Family expenses	2,066	-	-	2,379	-	-	-
Lost employment (parents)	4,025	-	-	4,025	-	-	-
<b>Subtotal</b>	14,844	71,613	74,576	15,235	71,311	72,715	82,468
Lost employment (person with ASD)	21,617	21,617	21,617	24,455	24,455	24,455	24,455
<b>Total (excluding benefits)</b>	36,460	93,230	96,193	39,690	95,767	97,171	106,923
Benefits	-	-	-	7,324	4,720	4,720	1,011
<b>Total (including benefits)</b>	36,460	93,230	96,193	47,014	100,487	101,891	107,934

1 Knapp, M., Romeo, R. & Beecham, J. (2007) *The Economic Consequences of Autism in the UK*, Report to the Foundation for People with Learning Disabilities, London.

2 Knapp, M., Romeo, R. & Beecham, J. (2009) Economic cost of autism in the UK, *Autism*, 13, 3, May, 317-336.

### 8.3 The costs of community-based care of technology-dependent children

A study led by Caroline Glendinning and Susan Kirk investigated the costs of supporting a group of children dependent on medical technology which enables them to survive.<sup>1,2</sup> The definition of technology dependence crucially affects estimates of the numbers of such children and for the purpose of the study was defined as: dependence on technological device to sustain life or optimise health and the need for substantial and complex nursing care for substantial parts of the day and/or night. Exemplar case studies of three technology dependent children were constructed in order to demonstrate the costs of caring for a technology dependent child at home. These case studies were designed to illustrate the wide range of medical, nursing and other needs of technology dependent children. They are not precise descriptions of any three particular families. Instead of drawing on 'real life' cases, they are designed to illustrate the wide range of medical, nursing and other needs of technology dependent children.

The following aspects of care were costed:

- One-off capital/start-up costs (mainly the purchase of equipment)
- Recurrent costs of equipment and consumables
- Recurrent staffing costs
- Recurrent statutory social security benefits
- Additional costs borne by families themselves (partially offset by social security benefits)

The costs summarised below have been derived from a number of sources. The costs of specialist equipment and associated consumables, home care services and enteral feeding were supplied by staff at two specialist regional hospitals. Information on the costs of community health and local authority services were originally obtained from Netten et al. (1998).<sup>3</sup> Details of professional salary costs were obtained from the 1999 report of the relevant pay review bodies. These costs have been uprated to reflect the present day costs. Costs borne by families themselves which were similar to those incurred in the care of a severely disabled child were obtained from a study which used budget standard methods to estimate the costs of childhood disability (Dobson and Middleton, 1998).<sup>4</sup> The costs of other extra consumer items needed by families themselves were obtained from mainstream High Street suppliers. The annual costs of supporting technology-dependent children are presented.

Another study entitled Resource use and service costs for ventilator-dependent children and young people in the UK by Jane Noyes, Christine Godfrey and Jennifer Beecham, can be found at <http://www.blackwell-synergy.com/doi/pdf/10.1111/j.1365-2524.2006.00639.x>. This presents the resource use and costs involved in supporting ventilator-dependent children and young people at home compared with those in hospital.

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1 Glendinning, C., Kirk, S., Guiffrida, A. & Lawton, D. (2001) Technology-dependent children in the community: definitions, numbers and costs, *Child Care Health and Development*, 27, 4, 321-334.

2 Glendinning, C., Kirk, S., with Guiffrida, A. & Lawton, D. (1999) *The Community-Based Care of Technology-Dependent Children in the UK: Definitions, Numbers and Costs*. Research Report Commissioned by the Social Care Group, Department of Health, National Primary Care Research and Development Centre, University of Manchester.

3 Netten, A., Dennett, J. & Knight, J. (1998) *Unit Costs of Health and Social Care 1998*, Personal Social Services Research Unit, University of Kent, Canterbury.

4 Dobson, B. & Middleton, S. (1998) *Paying to Care: The Cost of Childhood Disability*, Joseph Rowntree Foundation, York.

### 8.3.1 Technology dependent children: Case A

Type of case		
<p>Case study A was a 6 year old girl with a congenital neuromuscular condition who needed continuous ventilatory support and was fed by a gastrostomy; she was also incontinent. Her divorced mother gave up work as a secretary to care for her and they lived in local authority housing which was adapted to provide a downstairs bedroom and bathroom. They had no car, so used taxis or pay friends to take A out. She attended a special school and received home visits from an outreach nurse from the specialist regional hospital 10 miles away, monthly visits from the local paediatric nursing team and physiotherapy once a week. A's mother had round the clock help from a team of specially trained home carers (who also care for A at school); some home help for housework and to take A's sibling to school; and quarterly visits from a social worker. She also received counselling and medication to help cope with the stress of caring for A. She had extra phone bills and the costs of refreshments for the home carers, over and above those normally associated with a severely disabled child.</p>		
Items	Average cost per annum 2009/2010	Description of items
Equipment non recurrent costs	£11,691	Includes housing adaptation, bed, wheelchair, two ventilators, electricity generator, pulse oximeters, two suction machines, one humidifier. Costs have been annuitised over a lifetime of 4-6 years at a discount rate of 3.5 per cent. Housing adaptation costs were annuitised over a lifetime of 10-15 years.
Equipment recurrent costs	£16,345	Includes clinical waste removal service, consumables, servicing ventilator, pulse oximeters, servicing suction machines and humidifier and gastrostomy feeding.
Annual staffing costs	£139,501	Based on a health care assistant, qualified nursing supervision, community nursing input, specialist outreach nurses, GP involvement, social worker involvement home help type input, community and hospital paediatricians, community children's nurse, community physiotherapist, OT and social worker and teacher.
Consequences of health costs to mother	£823	Includes prescription for anti-depressants, counselling from psychologists and GP appointments.
Social security benefits	£13,706	Includes income support and premium for lone parent, child allowance, disabled child premium, highest care DLA, highest care mobility DLA.
Education	£3,517	Includes transport to the school by taxi and community therapist input.
Family costs	£16,320	Includes increased electricity bills, laundry and clothing, incontinence and consumables, travel costs, home carers, telephone calls to hospitals, purchase of mobile phone and loss of earnings.
<b>Unit Costs Available 2009/2010</b>		
£201,907 total cost; £185,587 costs to state agencies;		

### 8.3.2 Technology dependent children: Case B

#### Type of case

Case study B was 4 months old. She suffered severe anoxia at birth, has a tracheostomy and was fed through a naso-jejunal tube. She was likely to be severely disabled. Her parents owned their house 50 miles from the regional specialist hospital. They had no personal transport. B's father switched from full to part-time work to help with her care. They had quarterly visits from a specialist outreach nurse from the hospital and monthly visits from the local district nurse, health visitor, occupational and physiotherapists and Portage workers. A weekly service removed clinical waste from the house. Trained home carers provided a break for B's parents three nights a week. A social worker was involved in multi-disciplinary planning/review meetings about B. B's parents used taxis or paid relatives' petrol costs instead of public transport, purchased a mobile phone and spent extra on phone calls to hospital.

Items	Average cost per annum 2009/2010	Description of items
Equipment non recurrent costs	£240	Includes suction machines and one humidifier. Costs have been annuitised over a lifetime of 4-6 years at a discount rate of 3.5 per cent.
Equipment recurrent costs	£5,150	Includes clinical waste removal service, consumables, servicing suction machines and humidifier.
Annual staffing costs	£25,480	This includes a home carer support, a specialist outreach nurse, GP involvement, social worker involvement, district nurse, health visitor, community therapist, OT, physiotherapist, portage worker, paediatricians, and district nurse.
Social security benefits	£7,479	Invalidity care allowance and highest care DLA.
Family costs	£7,335	Costs for all cases ranged from £6,070 to £8,600.
<b>Unit Costs Available 2009/2010</b>		
£45,684 total costs; £38,349 costs to state agencies.		

### 8.3.3 Technology dependent children: Case C

#### Type of case

Case study C was an 11-year old boy with renal failure. He received continuous cycling peritoneal dialysis every night and overnight feeding through a gastrostomy. He lived with his younger sibling in an owner-occupied house, which has had some minor adaptations to improve hygiene and storage facilities. His father worked full time; his mother cut her hours and lost promotion opportunities because of C's care. They owned their own car. C lived 20 miles from the specialist hospital, which he attended regularly for outpatient monitoring; both parents therefore needed extra time off work and incurred associated travel costs. C was visited at home each month by a specialist outreach nurse and also had annual visits from the dietician and social worker based at the hospital. C attends mainstream school, but requires no extra support there. However, his parents have bought mobile phones/pagers in case of an emergency.

Items	Average cost per annum 2009/2010	Description of items
Equipment non recurrent costs	£1,322	Includes dialysis machine. Costs have been annuitised over a lifetime of 4-6 years at a discount rate of 3.5 per cent.
Equipment recurrent costs	£46,478	Includes clinical waste removal service, consumables, gastrostomy feeding and associated drug therapy.
Annual staffing costs	£943	Includes a specialist outreach nurse, hospital dietician involvement, hospital social worker involvement and GP involvement.
Social security benefits	£3,145	Includes highest care DLA.
Family costs	£4,456	Includes increased electricity bills, laundry and clothing, travel costs, home carers, telephone calls to hospitals and loss of earnings.
<b>Unit Costs Available 2009/2010</b>		
Total costs 56,344; Costs to state agencies £51,888.		

## 8.4 Services for children in care

The following schemata present illustrative costs of children in care reflecting a range of circumstances. Information from practitioners and managers, gathered in the course of developing unit costs for social work processes, indicated that the prevalence of children within the care population who display the following attributes — or combinations of them — is likely to have an impact on the cost of placements: disabilities; emotional or behavioural difficulties; and offending behaviour.<sup>1</sup> Unaccompanied asylum seeking children comprise a further group whose circumstances, rather than their attributes, engender a different pattern of costs. In any population of looked after children, there will be some children who have none of these additional support needs. Authorities with a higher proportion of children without additional needs will incur lower average costs per looked after child. However in reality their overall expenditure on children's services may be greater, for such authorities may place a higher proportion of their whole population of children in need away from home than do those with better developed family support services.

The study by Ward and colleagues identified different combinations of additional support needs. There were five simple groups of children who display none or one of the exceptional needs expected to affect costs, and six complex groups of children who display two or more additional support needs. In the sample of 478 children, 129 (27 per cent) showed no evidence of additional support needs, 215 (45 per cent) displayed one; 124 (26 per cent) children displayed combinations of two; and a very small group of children (2 per cent) displayed combinations of three or more.

The care package costs for children described in the schemata illustrate an example of the support received by a child in some of these groups, taken from the study sample. Costs relate to time periods stated in the individual schemata.

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<sup>1</sup> Ward, H., Holmes, L., Soper, J. & Olsen, R. (2004) *Costs and Consequences of Different Types of Child Care Provision*, Centre for Child and Family Research, Loughborough University.

### 8.4.1 Children in care: low cost — with no evidence of additional support needs

Child A is a boy aged fourteen with no evidence of additional support needs. These costs show the total cost incurred by social services and other agencies from February 2000 to October 2001 updated using the PSS Pay & Prices inflator. He first became looked after at the age of six, as the result of neglect. Since then he has been placed with the same local authority foster carers — a placement that had lasted eight years by the start of the study. In June 2001, his case was transferred to the leaving care team. Reviews were held at six monthly intervals and his care plan was updated every six months. He attended six monthly dental appointments and an annual looked after child medical. During the time period shown above, this young person attended weekly, hour-long physiotherapy sessions as a result of a neck injury. A care order was obtained in 1992. He completed his statutory schooling in summer 2001 and obtained seven GCSEs. He attended mainstream school until Summer 2000. He then progressed to further education to start an A level course.

Child A had a relatively inexpensive placement with local authority foster carers. He incurred some educational costs, in that he attended school, and some health care costs, but there was no exceptional expenditure. Please note that these figures have been rounded. Where appropriate, the original information has been adjusted to take account of Agenda for Change salaries.

Process	Cost to LA	Total £	Cost to others	Total £
Care planning	£134 x 3	401	£164 x 3	493
Maintaining the placement	£540 x 87 weeks minus £6,660 <sup>1</sup>	40,320	£53 x 3	158
Review	£453 x 3 + £13 <sup>2</sup>	1,372		
Legal	£5.26 <sup>3</sup> x 87 weeks	458	£9.80 <sup>4</sup> x 87 weeks	849
Transition to leaving care	£1,292	1,292		
<b>Cost of services</b>				
Mainstream schooling			£25 <sup>5</sup> per day	7,062
FE college			£25 <sup>6</sup> per day	780
Dentist			£8.30 <sup>5</sup> x 3	25
Looked after child medical			£32 <sup>7</sup>	32
Physiotherapy			£56 x 87 weeks	4,914
<b>Total</b>		<b>£43,843</b>		<b>£14,313</b>

1 Cost includes payment made for the placement and all activity to support the placement. There is a reduction in cost as a result of reduced activity once the placement has lasted for more than one year.

2 An additional cost is incurred for the first 16+ review.

3 The cost of obtaining a care order has been divided over the total number of weeks between admission and the child's eighteenth birthday.

4 Selwyn, J., Sturgess, W., Quinton, D. & Baxter, K. (2003) *Costs and Outcomes of Non-Infant Adoptions*, Bristol University, Bristol.

5 Berridge, D., Beecham, J., Brodie, I., Cole, T., Daniels, H., Knapp, M. & MacNeill, V. (2002) *Costs and Consequences of Services for Troubled Adolescents: An Exploratory, Analytic Study*, University of Luton, Luton.

6 Provisional cost based on the cost of mainstream schooling taken from Berridge, D. et al (2002) *Costs and Consequences of Services for Troubled Adolescents: An Exploratory, Analytic Study*, University of Luton, Luton.

7 Based on the unit cost of a surgery consultation with a general practitioner (see Schema 10.8b)

## 8.4.2 Children in care: median cost — children with emotional or behavioural difficulties

At the start of the time period until April 2001, Child B was placed with local authority foster carers (within the area of the authority). She then changed to another placement with local authority foster carers within the area of the authority. A care order was obtained for this young person when she first became looked after in March 1995. During the time frame three review meetings were held and her care plan was also updated on three occasions. Child B attended mainstream school during the time period. From December 2000 until June 2001 she received support from a personal teaching assistant for four hours a week. This young person attended six monthly dental appointments and also her annual looked after child medical. Child B received speech therapy until July 2001. Following a self-harm incident she was taken to the accident and emergency department. As a result of this incident she was referred to a clinical psychologist and began weekly sessions in September 2000.

Costs to social services are relatively low, largely because she was placed with local authority foster carers within the area of the authority throughout the study period. Although she did experience a change of placement the costs of this change were relatively low because she was not classified as difficult to place. There were relatively high costs to other agencies, designed to meet both her health and educational needs. Please note that these figures have been rounded. Where appropriate, the original information has been adjusted to take account of Agenda for Change salaries.

Process	Cost to LA		Cost to others	
	Unit costs	Total £	Unit costs	Total £
Care planning	£134 x 3	401	£164 x 3	493
Maintaining the placement	£481 x 87 weeks minus £4,976 plus £318 <sup>1</sup>	37,189		
Finding subsequent placement	£227	227		
Review	£453 x 3	1,360	£53 x 3	158
Legal	£6.40 <sup>2</sup> x 87 weeks	558	£11.80 <sup>3</sup> x 87 weeks	1,028
<b>Cost of services</b>				
Mainstream schooling			£25 <sup>4</sup> per day	7,855
Dentist			£8.30 <sup>4</sup> x 3	25
Looked after child medical			£32 <sup>5</sup>	32
Speech therapy			£53 x 60 weeks	3,158
Clinical psychologist			£89 x 52 weeks	4,606
Hospital accident and emergency visit			£107	107
Personal teaching assistant			£42 <sup>4</sup> (4 hrs per week for 25 weeks)	4,237
<b>Total</b>		<b>£39,735</b>		<b>£21,697</b>

1 Cost includes the payment made for the placements and all activity to support the placements. There is a reduction in cost as a result of reduced activity for the first placement which has lasted for more than one year. There is an increase in cost in the first three months of the second placement due to increased social worker activity.

2 The cost of obtaining a care order has been divided over the total number of weeks between admission and the child's eighteenth birthday.

3 Selwyn, J., Sturgess, W., Quinton, D. & Baxter, K. (2003) *Costs and Outcomes of Non-Infant Adoptions*, Bristol University, Bristol.

4 Berridge, D., Beecham, J., Brodie, I., Cole, T., Daniels, H., Knapp, M. & MacNeill, V. (2002) *Costs and Consequences of Services for Troubled Adolescents: An Exploratory, Analytic Study*, University of Luton, Luton.

5 Based on the unit cost of a surgery consultation with a general practitioner (see Schema 10.8b)

### 8.4.3 Children in care: high cost — children with emotional or behavioural difficulties and offending behaviour

Child C was aged fifteen at the start of the study. He first became looked after at the age of eleven when his parents needed relief. Prior to the start of the study he was placed in secure accommodation on five separate occasions. He had also been placed in various residential homes, schools and foster placements, many of which had broken down. As a consequence he had been classified as 'difficult to place'. During the study period Child C experienced ten different placements. He also refused all statutory medicals and dental appointments, furthermore, he refused any mental health support. Child C did not complete his statutory schooling as a result of numerous exclusions and non-attendance. Prior to the start of the study he had a history of offending, this continued throughout the study with him committing ten further offences. He ceased being looked after in summer 2001 when he refused to return to any placement provided by the local authority.

The costs to social services were relatively high, both because of a number of out-of-authority, residential placements provided by agencies and due to nine changes of placement. There were substantial costs to other agencies (Youth Offending Team and the Police) as a result of his offending behaviour. Additional health care costs were not incurred for this young man because of his refusal to engage in the services offered to him. Please note that these figures have been rounded. Where appropriate, the original information has been adjusted to take account of Agenda for Change salaries.

Process	Cost to LA	Total £	Cost to others	Total £
Care planning	£134 x 2	267	£159 x 2	318
Maintaining the placement	£259,616 plus £1,167 <sup>1</sup>	260,783	£53 x 74 weeks <sup>2</sup>	3,922
Ceased being looked after	£293	293		
Find subsequent placements	£8,632 <sup>3</sup>	8,632		
Review	£453 + £905	1,358	£191 x 2	383
<b>Cost of services<sup>4</sup></b>				
YOT involvement/criminal costs			£1,080 <sup>5</sup> x 74 weeks	79,920
<b>Total</b>		<b>£271,333</b>		<b>£84,543</b>

1 This cost includes the payment made for the placement and all activity to support the placements. There is an increase in cost in the first three months of a placement due to increased social worker activity.

2 Child C ceased being looked after in July 2001, therefore the time period being costed is 74 weeks.

3 Child C experienced nine changes of placement during the timeframe of the study.

4 There are no additional education costs because these are included in the costs of the placements in process three.

5 Costs taken from Liddle, M. (1998) *Wasted Lives: Counting the Cost of Juvenile Offending*, National Association for the Care and Resettlement of Offenders, London.

### 8.4.4 Children in care: very high cost — children with disabilities, emotional or behavioural difficulties plus offending behaviour

Child D experienced nine different placements from February 2000 to October 2001. Initially he was placed in an agency residential unit with education facilities out of the area of the authority. In March 2000, he was placed with agency foster carers, again out of the area of the authority. He then experienced three further placements, all out of the area of the authority and all provided by agencies: another residential unit, then another foster placement, then a third residential placement. In September he was placed overnight in a secure unit within the area of the authority. He was then placed with agency foster carers followed by a further agency residential unit before moving to a specialised one bedded, agency, residential unit in December 2000. This placement was also out of the area of the authority. Review meetings were held six monthly and his care plan was also updated every six months. This young person attended the education provision in two different residential units up until summer 2000, when he was permanently excluded. He then started sessions with a home tutor in October 2000. During the given time period he attended six monthly dental appointments and his looked after child medical. He also attended weekly sessions with a clinical psychologist from October 2000 onwards. In September 2000, he committed a criminal offence, the police were involved, but he was not convicted.

These costs are markedly higher than for the majority of other children in the sample. Child D had become 'difficult to place' and increasing amounts of social work time had to be spent on finding the rare placements that were prepared to accept him. The costs of changing placements were calculated at over £1,000 per move. Please note that these figures have been rounded. Where appropriate, the original information has been adjusted to take account of Agenda for Change salaries.

Process	Cost to LA	Total £	Cost to others	Total £
Care planning	£67 x 3	200	£164 x 3	493
Maintaining the placement	£496,340 plus £1,274 <sup>1</sup>	497,613		
Finding subsequent placements	£11,136	11,136	£90 x 8 <sup>2</sup>	719
Review	£905 x 3	2,715	£388 x 3	1,163
Legal	£3.40 <sup>3</sup> x 87 weeks	296	£6.00 <sup>4</sup> x 87 weeks	522
Transition to leaving care	£1,292	1,292		
<b>Cost of services</b>				
Home tuition			£42 <sup>5</sup> per hour	8,050
Permanent exclusion			£144 <sup>6</sup>	144
Dentist			8.30 <sup>5</sup> x 3	25
Looked after child medical			£32 <sup>7</sup>	32
Clinical psychologist			£89 per hour for 52 weeks	4,628
Police costs for criminal offence			£222 <sup>8</sup>	222
<b>Total</b>		<b>£513,252</b>		<b>15,999</b>

- 1 The cost includes the payment made for the placements and all activity to support the placements. There is an increase in cost in the first three months of a placement due to increased social worker activity.
- 2 Child D experienced eight changes of placement during the timeframe of the study.
- 3 The cost of obtaining a care order has been divided over the total number of weeks between admission and the child's eighteenth birthday.
- 4 Selwyn, J., Sturgess, W., Quinton, D. & Baxter, K. (2003) *Costs and Outcomes of Non-Infant Adoptions*, Bristol University, Bristol.
- 5 Berridge, D., Beecham, J., Brodie, I., Cole, T., Daniels, H., Knapp, M. & MacNeill, V. (2002) *Costs and Consequences of Services for Troubled Adolescents: An Exploratory, Analytic Study*, University of Luton, Luton.
- 6 Parsons, C. & Castle, F. (1998) The cost of school exclusion in England, *International Journal of Inclusive Education*, 2, 4, 277-294.
- 7 Based on the unit cost of a surgery consultation with a general practitioner (see Schema 10.8b).
- 8 Liddle, M. (1998) *Wasted Lives: Counting the Cost of Juvenile Offending*, National Association for the Care and Resettlement of Offenders, London.

## 8.5 Young adults with acquired brain injury in the UK

ABI is 'a non-degenerative injury to the brain occurring since birth' including both open and closed head injuries. ABI includes a range of diagnoses or causes including strokes or tumours; head injury through trauma is a common cause among young adults. ABI is not thought to affect life expectancy after the initial acute phase, so the prevalence of long-term brain damage is high at 100-150 per 100,000 population, implying a total of 60,000-90,000 people in the UK ([www.rhn.org.uk](http://www.rhn.org.uk)).

A study carried out by the Personal Social Services Research Unit was undertaken to identify the health and social care services used by young adults aged 18-25 years with acquired brain injury (ABI) and the associated costs.<sup>1</sup> The study identified the annual incidence of ABI in this age group and then tracked the young adults' likely progress through four support-related stages: trauma, stabilisation, rehabilitation and return to the community. By identifying the numbers using different treatment locations and services at each stage, a picture of service use and costs could be built up over a notional 12-month period following injury. All costs have been updated to 2009/2010 prices using the HCHS Pay and Prices Inflation.

Four broad groups of young people with ABI were identified by their location and the community care stage as follows:

Group 1 comprises the largest proportion of those sustaining brain injuries and includes those who attend A&E with ABI or spend short periods in a hospital ward and then return home. A small proportion- perhaps just one in five- will have follow-up appointments arranged at an outpatient clinic or with their GP. This group will generally have had a mild head injury and no longer-term disability, although 20 per cent of this group may continue to have residual symptoms 6 months after injury.

Group 1: Average cost per person = £289 p.a.

People in Group 2 are also likely to have returned to their own homes within a year, but are more seriously disabled and rely on personal care support provided by spouses, parents or other informal carers. This group may include those who are discharged home from longer-term residential rehabilitation (34 per cent of patients discharged), from acute brain injury units (25 per cent) and from neurosurgery units (23 per cent). It is likely that at least 40 per cent of them will require at least part-time support or supervision from informal carers.

Group 2: Average costs per person = £20,647 p.a.

The third group of young adults with ABI are those whose pathway towards the end of a year will see them living in supported accommodation with formal (paid) personal carers. Some will have been discharged straight from hospital and some will have stayed in a rehabilitation facility prior to their move to supported living. One in four of these young adults will need overnight supervision and three in four will need at least part-time supervision during the day. The number of young adults may be quite high, but some will move on to more independent living. Others will need this type of support for many years to come. For cost estimates, it has been assumed this group will live in community-based housing with low staffing levels during the day and 'sleeping-in' staff at night. In addition to personal care they are also likely to use outpatient clinics and community-based therapists. Personal care costs (estimated at an average of 8 hours overnight 'sleeping-in' and 6 hours during the day) would amount to £517 per week. Use of community-based therapy and health care services would add another £601 by the end of the notional 12 month period.

Group 3: Average cost per person = £39,585 p.a.

The fourth group includes young adults who are likely to be among the most severely disabled. Although some will be supported at home, it is estimated that 310 will be resident in nursing homes for young adults, specialist ABI residential units, in longer-stay hospital wards or in mental health units. They are likely to have been the most severely injured. Some of the principal independent providers contacted for this research reported current prices for residential placements of up to £3,007 per week, often jointly funded by health and social services. Nursing homes and 'young disability units' are likely to be less costly. However nursing home care may not be appropriate for people with severe ABI-related disability as there tend to be few qualified staff and low input from local community-based teams or specialist doctors.

Group 4: Average cost per person = £40,788 p.a.

<sup>1</sup> Beecham, J., Perkins, M., Snell, T. & Knapp, M. (2009) Treatment paths and costs for young adults with acquired brain injury in the United Kingdom, *Brain Injury*, 23, 1. 30-38.