THE ECONOMIC CONSEQUENCES OF AUTISM IN THE UK

Martin Knapp
Renée Romeo
Jennifer Beecham

Foundation for People
with Learning Disabilities

Acknowledgements

This study was funded by The Shirley Foundation and was carried out at the Centre for the Economics of Mental Health, King's College London, Institute of Psychiatry, with advice from the Foundation for People with Learning Disabilities. In the course of our work we benefited enormously from help and advice from a number of people. Nevertheless, the views expressed here are those of the authors and not necessarily those of the funders.

We would like to thank Oliver Chadwick, Tony Charman, Sally-Ann Cooper, Eric Emerson, David Felce, Hilary Gilfoy, Tamsin Ford, Brian Jacobs, Krister Järbrink, Sally Mallam, Jim Mansell, Manuel Posada, Poul Thorsen, Bharti Rao, Mike Rutter, Tricia Sloper, Peter Tyrer, Janet Robertson, Paul Swift and members of the Autism All Parliamentary Party Group for giving us expert advice at various key stages of our research and/or access to data.

Contents

Foreword 1

Executive Summary 2

Introduction 4

Methodology 6

Results 14

Discussion 23

References 25

Foreword

The Shirley Foundation is pleased to sponsor this study of the economic impact of autistic spectrum disorders in Britain. This follows the seminal study the Foundation also initiated and sponsored in 1999 which – as one would expect from Professor Martin Knapp and his team – has now been developed with considerably more sophistication in methodology.

The conclusion as to lifetime costs is, despite inflation, little changed from the earlier study. However, the increase in measured incidence and the number of life years of autism (which exceed those lived with Alzheimer's disease) generate a national cost of £28 billion a year - a figure reinforced by economic research in Australia.

May this quite astonishing finding mobilise researchers, families, politicians, autism charities and our public servants to become activists in demanding answers to The Big Question of what causes the disability associated with autism. That way lies hope, lies funding, lies effective interventions and lies choice for people with autistic spectrum disorder and their families. Ultimately, further research and development can help us reduce the economic burden associated with this disability and, even more importantly, help improve the lives of individuals and families.

Dame Stephanie Shirley
In memory of her late son Giles

Executive summary

Autism has life-time consequences with a range of impacts on the health, economic wellbeing, social integration and quality of life of individuals with the disorder, and also on their families and potentially the rest of society. Many of those impacts can be expressed as economic costs. The purpose of the research detailed in this report was to estimate the full costs of autism spectrum disorders (ASDs) in the UK.

There is no single, nationally representative data set that would allow us to estimate prevalence, service use and costs for the same group of people. We therefore adopted a modular approach with four elements – prevalence, level of functioning, place of residence, and cost per individual – and sought to obtain the best and most up-to-date UK estimates for each. In this way we were able to calculate the aggregate costs of autism spectrum disorders.

Data came from a variety of sources, including: national surveys, published research, our own previous studies and expert advice.

Costs for children

Annual costs for children with low-functioning ASD who are living in residential or foster placements were estimated to be £16,185 (for children aged 0-3 years), £40,578 (aged 4-11) and £62,536 (aged 12-17). Costs were considerably lower if children with low-functioning ASD lived with their families: £585 (if aged 0-3), £23,869 (aged 4-11) and £36,474 (aged 12-17). Average annual costs for children with high-functioning ASD ranged from £1,214 to £21,090. These costs exclude informal care by families.

Costs for adults

For adults, we again made the distinction between low and high-functioning ASD. Imputed costs for lost employment were included for both the individuals with ASD and their parents, where these are appropriate. We estimated that an adult with high-functioning ASD living in a private household cost £32,681 per annum. For a high-functioning adult living in supported accommodation or a care home, costs are much higher (£84,703 and £87,299 respectively). Mean annual costs for low-functioning adults were found to be £36,507 for those living in private households, £87,652 in supported accommodation, £88,937 in residential care, and £97,863 in hospital.

Total annual UK costs

We multiplied these individual-level costs by estimates of prevalence rates, distinguishing type of accommodation, level of functioning and age group. The aggregate national costs of supporting children with ASD were estimated to be £2.7 billion each year. Most of this cost is accounted for by services used. For adults, the aggregate costs for adults amount to £25 billion each year. Of this total, 59% is accounted for by services, 36% by lost employment for the individual with ASD, and the remainder by family expenses.

Lifetime costs

The lifetime cost for someone with high-functioning autism was found to be £2.9 million and £4.7 million for someone with low-functioning autism.

Relevance of these estimates

What makes these new cost estimates so relevant today? There are four broad reasons. In the first place, our estimates span all areas of public sector expenditure, including education and housing, demonstrating not only the high support costs for people with ASD but also the breadth of those costs. Second, this analysis recognises the high cost to families, in terms of out-of-pocket expenses, lost income and lost employment opportunities. We could not include the time costs for family members who care for an individual with ASD, but there is no doubt that these will be considerable. This recognition of the high support costs for ASD leads to two further reasons why these new estimates are important. Firstly, there are early interventions available that help alter behaviour patterns. Would increased investment in these reduce high support costs in adulthood? Secondly, a greater availability of effective early interventions may reduce the impact of ASD on the UK economy as well as improve quality of life for people with ASD and their families.

Introduction

Prevalence and impacts

Published reports suggest that autistic spectrum disorders (ASDs) are more common than was previously estimated (Filipek *et al*, 1999; Baird *et al*, 2006; Chakrabarti & Fombonne, 2005). A recently published estimate suggests that ASD affects 116 in every 10,000 children aged 9-10 years (Baird *et al*, 2006), compared with an estimate of 20 per 10,000 less than two decades ago (Aitken, 2001). To what extent this represents a real underlying increase in prevalence rather than changes in diagnostic criteria or improvements in identification is hard to say (Wing, 1993; Le Page, 2001; Lawton, 2005; Aitken, 2001), and is the subject of considerable public debate. What is agreed, however, is that there is much greater public awareness of autism today than ever before.

There is also little doubt that disorders on the autistic spectrum have enormous implications for the lives of individuals with disorders and the lives of their families. Those implications will be especially large when someone with ASD also has a moderate or severe intellectual disability. The consequences of ASD can be seen in many domains, including family and other relationships, employment, leisure activities, standards of living, social and personal functioning, and of course an individual's and a family's quality of life more broadly. These consequences tend to persist through childhood and into adulthood. Their impacts on the health, economic and social wellbeing of individuals, their families and the rest of society also vary from individual to individual depending on a variety of factors.

The earliest studies of ASD in adult life showed that many individuals had high dependency for support, with the majority of adults living with parents, in institutional facilities or sheltered accommodation (Rutter *et al*, 1967; Rutter & Lockyer, 1967; Lockyer & Rutter, 1969). Only a minority of individuals with autism and low IQ achieve independence (Howlin *et al*, 2004a). Among individuals with higher levels of cognition – people with high-functioning autism (conventionally defined as having IQ of 70 or over) – deficits or difficulties in the dimensions associated with ASD (and in particular in relation to repetitive behaviour) may outweigh positive outcomes associated with a higher IQ (Howlin *et al*, 2004b).

Treatment and support

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.

However, the availability of suitable interventions or supports remains low (and unevenly spread), so that the burdens and stresses experienced by families tend to persist (Wong & Smith, 2006; Smith *et al*, 1994). Indeed, family stresses related to the care of children with ASD have been shown to be significantly greater than the stresses experienced in the care of children with other developmental disorders (Sander & Morgan, 1997; Bromley *et al*, 2004). It is therefore not surprising that parents of children with ASD are seen to be at high risk of developing mental health problems (Piven and Palmer, 1999; Ryde-Brant, 1990; Wolf *et al*, 1989).

As well as bearing the practical burdens and perhaps psychological stresses of having a child with ASD, and facing family disruption and in some cases even breakdown, many parents and carers also experience disruption to their employment, constraints on career progression and consequent losses in earnings (Järbrink *et al*, 2003).

Research aims

The purpose of the study summarised in this report was to examine the service, family and other economic consequences of ASD in the UK. We were commissioned to achieve two things. One aim was to estimate the economic consequences of autism in the UK, both for children and adults with ASDs, with and without an intellectual disability. The second aim – which we do not address in this report, although we have almost finished the associated empirical research – was to examine whether potentially there are longer-term economic benefits from investments in a range of early intervention services and supports for children with ASDs.

Report structure

In the next section of this report we start by giving a general outline of the methodology used in our identification and estimation of the economic consequences of ASD. We then describe how that broad approach was implemented, including a description of the datasets from which we extracted relevant information (for example on individuals with autism), how we weighted and combined those data, and how the costs were estimated.

The next section gives our main findings. We separate the findings for children and adults, because the methods we used were slightly different. In each case, we start with a discussion of prevalence, as this is the basic platform from which we will build the cost estimates. It will be seen that there are a number of different prevalence bases that could have been employed, especially when trying to distinguish between low- and high-functioning (often abbreviated to LF and HF) ASD. We then discuss the settings in which people with ASD are accommodated and the estimated numbers in those settings; we do so because accommodation is such an important driver of cost. The next step is to describe the people for whom we were able to gather evidence on service use, family support, lost employment and other elements that potentially have cost consequences. Bringing all of these pieces of information together – prevalence, level of functioning, place of accommodation and costs – we are able to estimate the overall and component costs of ASD. We summarise our analyses of service use patterns and costs, discussing (among other things) the extent to which people with ASD are able to participate in special and further/higher education, day activities and employment.

The final section of the report offers a preliminary discussion of these findings, concentrating mainly on their policy implications.

Methodology

Overview of the methodological approach: modular

It is helpful to give an overview of the approach that we have taken. First we need to describe the limitations of existing data as these help to explain our approach.

Limitations of existing evidence: Estimating the overall cost of ASD, and components thereof, was made especially difficult by the limited availability of UK data on key pieces of information. There are, for example, continuing discussions as to the overall prevalence of ASD, and the constituent prevalence figures for Asperger's, childhood autism, atypical autism, pervasive developmental disorder (PDD) not otherwise specified, and so on. This makes it difficult to estimate total numbers of children or adults with different diagnoses within the spectrum.

A second set of missing information related to the places of accommodation for people with ASD, particularly in adulthood. Although it could be assumed that most adults with high-functioning autism were living in ordinary community accommodation (i.e. in private households, whether alone, with a partner, with parents, or with others), the place of residence for adults with autism and intellectual disability (low-functioning ASD) is a more complicated matter. A minimal categorisation of accommodation types would be to distinguish private households (whether living alone, with a partner, with parents, in an adult foster placement or similar) and some form of congregate care setting. However, the latter includes a tremendous variety of types of setting, including supported housing, unstaffed group homes, staffed group homes, residential care facilities, NHS in-patient wards (on a long-stay basis) and private and voluntary sector facilities (hospitals or similar). These various accommodation settings cost different amounts, making it important that our study endeavoured to identify the numbers of people with ASD by place of residence.

A third area where information was missing was more specific: we could find little useful information that would help us to estimate costs of supporting adults with high-functioning autism.

We also had difficulty finding information in either the published literature or our datasets on service use patterns or costs of supporting children of pre-school age. We have therefore used information provided by Tony Charman (personal communication) to estimate costs in this age group. However, we are aware that some research evidence is emerging for this age group: the Preschool Autism Communication Trial (PACT) due to be completed in 2009 is the first large-scale study of its kind in autism. It will test the effectiveness and cost-effectiveness of a treatment given by speech and language therapists that helps parents adapt their communication to the needs of their child.

Given these difficulties, and given that there is no single nationally representative data set that would allow us to estimate prevalence, service use and costs for the same group of people, we adopted a modular approach with five elements:

- Prevalence
- Level of functioning
- Place of residence
- Cost per individual
- Aggregate cost

Prevalence estimates

Estimates of prevalence were sought from the literature, and from leading epidemiological experts in the autism field. We were unable to influence the ways in which previous prevalence studies categorised the population, whether in terms of age groups or diagnoses, and therefore had to use what was available and then try to marry those available prevalence estimates with information from other sources that would allow us to attach costs. We have, as far as possible, relied heavily on the most recent estimates available.

The estimates suggested from the literature and from expert advice are as follows:

- The most recent published estimate is offered by Baird and colleagues, (2006) who estimated the prevalence of autism among 9-10 year olds in South-East England to be 38.9 per 10,000; other ASDs as 77.2 per 10,000 and all ASDs as 116.1 per 10,000. This is at the high end of the range of prevalence estimates.
- The overall prevalence estimate for children aged 5-16 from the national survey of the Mental Health of Children and Young People in Great Britain, conducted in 2004, was 0.9% (Green *et al*, 2005).
- Eric Fombonne, (2005) offered 'conservative' estimates of 13 per 10,000 for autistic disorders; 20.8 per 10,000 for PDD-NOS ; 2.6 per 10,000 for Asperger's syndrome; and 36.4 per 10,000 for all PDDs.

For our calculations we use a prevalence estimate of 1% across all ages, which is slightly lower than the figure from the recent Baird study, but is the figure recommended for our "all-ages" approach by Tony Charman (personal communication).

Level of functioning

These prevalence estimates help us to estimate how the populations of children and adults with ASD can be disaggregated, a task which is necessary given the heterogeneity of needs and circumstances – and hence probably also of costs – within the group of people with ASD. After considering a number of options we have simply distinguished two groups: people with low-functioning and high-functioning autism (IQ below and equal/above 70, respectively). Finer classifications might be possible with available epidemiological data, but there would be difficulties matching prevalence numbers to data on place of residence and cost.

In our analyses we therefore distinguish the following groups within the population:

- Pre-school children (ages 0-3) with high-functioning autism
- Pre-school children (ages 0-3) with low-functioning autism
- Primary school children (ages 4-11) with high-functioning autism
- Primary school children (ages 4-11) with low-functioning autism
- Secondary school children (ages 12-17) with high-functioning autism
- Secondary school children (ages 12-17) with low-functioning autism
- Adults (ages 18 and over) with high-functioning autism
- Adults (ages 18 and over) with low-functioning autism

The conventional cut-off between high- and low-functioning is an IQ of 70, and most of the data on which we relied used this cut-off. We distinguished three age groups in the child population because of the different costs associated with each, which appear to be driven partly by education stage. The oldest person with ASD in our datasets was aged 74, but we have assumed that costs for adults apply across the full expected lifespan.

Among the groups with low-functioning autism it would in principle be possible to distinguish people with mild, moderate, severe and profound intellectual disability. However, although we initially pursued this approach, it did not prove possible to find robust prevalence figures for the subgroups, nor were we able to find much cost information for these groups considered separately. We have therefore not been able to make that finer distinction within the low-functioning group.

Sources for data on how the overall ASD prevalence breaks down into low-functioning and high-functioning individuals include:

- Estimates provided by the National Autistic Society that draw on early work by Lorna Wing suggest that 78% of this population have high-functioning ASD (IQ of 70 or over), and 22% have low-functioning ASD (IQ under 70).
- Atladottir *et al*, (2007) examined Danish birth cohort data. Out of 1860 with ASD, 350 had Asperger's Syndrome, 714 had childhood autism, 145 had atypical autism, and 651 had PDD not otherwise specified.
- Figures provided by Manuel Posada (personal communication) suggest that 67% of children with ASD have autistic disorder and 33% have Asperger.
- The Morbidity and Mortality Weekly Report from CDC (9 Feb 2007) offers useful material from two Autism and Developmental Disabilities Monitoring Network estimates in the US. The percentages with cognitive impairment (hence low-functioning ASD) were (from the 2000 data): 46% (Arizona), 40% (Georgia), 62% (South Carolina); and (from the 2002 data) range from 33.1% (Utah) to 58.5% (South Carolina) around an average of 44.6%.
- The study by Baird *et al*, (2006) has an estimate of the percentage of children with an IQ below 70 of 55%.

As our base case assumption we have chosen the Baird estimate: 55% of people with ASD are assumed to be low-functioning, and 45% are high-functioning.

Place of residence

For each subgroup defined by age and functioning (e.g. primary school children with high-functioning autism) we looked for estimates of the costs of support. Because those costs are driven by the accommodation setting within which an individual lives, we first needed to describe the distribution of people with ASD across different accommodation types. We were unable to find any specific information on people with ASD, and so we have made the following assumptions corresponding to the various age-functioning groups:

- **Children with high-functioning ASD:** All were assumed to live with their parents.
- **Children with low-functioning ASD:** We drew on the Bebbington and Beecham (2007)

analyses of the Children In Need (CIN) data for 119 of the 150 local authorities in England in 2001. Those analyses show the number of children with ASD living in residential care or foster placements in England in 2001. These data compare well with the overall figures from the 2005 CIN survey but we have used the 2001 data as there are more details available for our purposes. We have assumed that all of these children had low-functioning autism: we do not know what IQ score cut-off was used by local authorities in describing some of this group as having intellectual disabilities. It may be that some of these children in residential care or foster placements would have been high-functioning, but it would make little difference to our cost estimates. Certainly 'disability' was overwhelmingly the primary reason for these children having 'looked after' status. These CIN figures for England were inflated to estimates for the UK by weighting by overall child population data. We then subtracted these numbers from the estimated total number of children (aged 4 and above) with low-functioning autism and assumed that the remainder were living in private households. We do not have any estimate for the number of children with autism living in hospitals, but have been advised that it would be very small, and we have assumed that it is zero.

- **Adults with high-functioning ASD:** A report by Barnard *et al*, The Reality for Adults with Autism Spectrum Disorders, published by the National Autistic Society (NAS) in 2001 gave us some broad indications. (However, the report did not give many precise statistical findings, and the representativeness of the sample is unclear as it was drawn from NAS membership. In addition, the survey had only a 38% response rate.) We have assumed that 79% of adults with high-functioning ASD live in private households, 5% in Supporting People accommodation, 16% in residential care and none in hospital. (See below for the reasons for this categorisation).
- **Adults with low-functioning ASD:** Accommodation arrangements for adults with ASD had to be estimated in the absence of any directly collected data on living arrangements. A recent and robust estimate of the distribution by type of accommodation for all adults with intellectual disabilities in England is provided by Emerson *et al*, (2005) in their report, Adults with Learning Difficulties in England 2003/04. On the basis of official statistics and published research, they estimated that 50% of adults with intellectual disabilities were living in private households with parents, 12% in private households with other relatives, 4% in private households alone, 3% in private households with partner, 11% in Supporting People accommodation, 19% in residential care, and 1% in hospital. The report by Barnard *et al*, (2001) again gave us broad indications of place of residence for low-functioning adults. We also received helpful advice from Eric Emerson that his team's calculated distribution for people with intellectual disability (ID) that we have just cited would not be a good indication of residence for people with low-functioning ASD. He advised us to assume proportionately fewer in private households and Supporting People arrangements (compared to the full population of people with ID) and proportionately more in NHS accommodation and registered residential homes. This was because of the higher prevalence of challenging behaviour among the ASD group. In the absence of any other information (everyone we approached for advice replied that they were not aware of any such data for any part of the UK) we have assumed the following percentage distribution for the UK as a whole: 31% of adults with intellectual disabilities were living in private households with parents or other relatives, 2% in private households alone, 2% in private households with partner, 7% in Supporting People accommodation, 52% in residential care, and 6% in hospital.

Costs

The costs to be attached to each of these age-functioning-setting groups were taken from previously conducted research, most of it by ourselves at the Centre for the Economics of Mental Health (King's College London) or the Personal Social Services Research Unit (London School of Economics and University of Kent), and some of it carried out specifically for this autism study. We wanted to use up-to-date cost estimates as these would reflect current service use patterns and expenditure levels in what is a fast-changing field. Where information was missing, we went to the best alternative source in order to estimate a cost. For example, as described below, we needed to take some data for children with high-functioning autism from a Swedish study, because we could find no estimates for the UK. We also relied a little on older data from our earlier study (Järbrink and Knapp, 2001).

We sought a number of different types of cost. We were obviously interested in service costs, whether those services were within the health system, social care system, education, housing, leisure, or other areas. Our interest is in costs that are due to ASD, and so we include the costs of special but not mainstream education, residential care but not private household accommodation and so on.

Second, we were interested in the costs to families and other carers, in terms of the hours of support provided and out-of-pocket payments for services. Third, we were interested in the opportunity costs of lost productivity from unemployment or disrupted employment, whether for individuals with ASD or their families. We were also interested in levels of social security/welfare benefit payments. One question to be addressed is the extent to which it is appropriate to attribute lost productivity costs to people with moderate or severe intellectual disability. Previous research has tended not to do so, but the emphasis on choice and opportunity in policy approaches such as Valuing People would suggest that inability (given present employment contexts and support arrangements) to work has an opportunity cost both to an individual and to society that it is utterly appropriate to include.

The costs attached to the support for children with ASD came from a variety of sources. For children in residential and foster placements we used figures from Bebbington and Beecham (2007), adjusted to 2005/2006 price levels. For children in private households we used cost estimates obtained from a pooled sample (see 'Datasets on children' below).

The costs attached to the different groups of adults also come from a variety of sources, and where possible we used the pooled data that we pulled together specifically for people with ASD (see 'Datasets on adults' below). Our pooled sample did not include anyone in hospital, and we have therefore taken the cost for that setting from the PSSRU Unit Costs volume.

Most of the studies used for our pooled estimates employed the same basic instrument (with adaptation) – the Client Service Receipt Inventory – to collect data on the use of supports and services for children and/or adults (Beecham and Knapp, 2001). There were two exceptions, one a study of children and the other a study of adults. All studies had used the same approach to unit cost calculation, and each had relied extensively on figures in the annual PSSRU compendium.

Datasets on children: The pooled dataset on children with ASD was drawn from four English studies of children with intellectual disabilities and/or mental health problems. We extracted from each of these datasets the information on all of those children with autism or diagnosed as having a pervasive developmental disorder (PDD). These data did not differentiate between the various types of ASD.

- In 2004 the Office of National Statistics (ONS) carried out a survey to estimate the prevalence of mental health problems among children and young people aged 5-16 in Great Britain. The survey was undertaken to update earlier estimates from 1999. Data collected included use of services. In the 2004 dataset, 67 children met the ICD-10 diagnostic classification for pervasive developmental disorder and were included in our pooled sample analysis.
- The second study was carried out by the Department of Child and Adolescent Psychiatry at the Institute of Psychiatry (Chadwick *et al*, 1998). It sampled 294 children with moderate or severe intellectual disability (IQ below 50). 18 children were diagnosed as having autism; their mean age was 8.2 years (the youngest was 5 and oldest 12). These children were then followed up into adolescence (mean age 13 years; range 11-16). There was no change in living arrangements over time: the group lived in private households and attended special schools.
- Third, we extracted data from a prospective cohort study of four child and adolescent units, two in the south of England and two in the north. These units had been included in a study of the process and outcome of inpatient child and adolescent psychiatry (Jacobs *et al*, 2004). Data were collected at four time points (pre-admission, at admission, at decision to discharge, and at one-year follow-up), but we only used the first of these datasets for our pooled analyses as these showed care pathways prior to admission to inpatient care. 14 of the 76 children in this study were diagnosed under the ICD-10 classification as having a pervasive developmental disorder, with a mean age of 11 years (the youngest child was 8 and the oldest 16).
- The final study was led by researchers from the Social Policy Research Unit at the University of York; with economic inputs from the Personal Social Services Research Unit at the University of Kent (Greco *et al*, 2005). 29 children from 177 families who answered questions on health and social services and 135 families on education or school-based services were identified as having autism. There was no information on age and gender for one of the children who was therefore dropped from the sample for our pooled analyses. The mean age of the sample was 10 years (the youngest child was 3 and oldest 17 years).

Datasets on adults: The data on adults with ASD were obtained from five studies on adults with intellectual disabilities. 4 of the 5 datasets were already available to us because of our involvement in those studies.

- Baseline service use data on 11 people diagnosed as having autism were extracted from a larger evaluation led by the Institute for Health Research at Lancaster University. That study examined the costs and outcomes of person-centred planning (Robertson *et al*, 2005). The mean age of the sample was 36 years (the youngest person was 17 and the oldest was 59).

- Adults diagnosed with autism were identified from a matched-group design study that compared the costs and quality of life outcomes of providing community accommodation for adults with intellectual disabilities with relatively low support needs either in fully staffed group homes or in semi-independent living (Perry *et al*, 2007). Service use data on 10 adults with a mean age of 53 years (ranging from 35 to 74 years) were used in the analysis.
- The third study was led by the Section of Psychological Medicine, University of Glasgow, and focused on the outcomes of a health screening programme (Cooper *et al*, 2006). Data were collected one year after screening. Of the 100 adult participants with intellectual disabilities who agreed to participate in the study, six were diagnosed with autism. The mean age of this sample was 41 (the youngest person was 20 and the oldest 64).
- In a further study by the same research team, to look at the prevalence of physical and mental illness in a population of intellectual disabled adults, there were 50 adults diagnosed with autism. Service use data were available. The mean age of the sample was 41 (ranging from 20 to 64 years). This was the only adult study in which we were not already involved.
- Finally, we drew data out of an ongoing study of the use of neuroleptics in adults with intellectual disabilities and challenging behaviour. This is the NACHBID study led by Peter Tyrer of Imperial College, London, results from which will be reported shortly. Fourteen adults in that study sample were identified as having autism. The mean age of the sample was 42 years (ranging from 26 to 63 years).

Cost calculation: The data obtained from these studies were organised into service and other categories as follows: hospital services, other health and social services, housing-based support (including residential accommodation and support), special education, other education support, day care provision, respite services, pharmacological and non-pharmacological treatments (where these were identified) and support for and by the family (including family expenses and family time costs associated with caring). Our cost-of-autism study was therefore conducted from a broad perspective.

As noted earlier, most unit costs for services were taken from the PSSRU annual Unit Costs of Health and Social Care compendium. Most of the studies from which we pooled data had already calculated the support and service costs. If necessary these costs were up-rated to 2005/06 price levels. We report these as annual cost equivalents.

Costs associated with the lost productivity due to unemployment or disrupted employment – for individuals with ASD or for families – were estimated from national figures for the average weekly wage of all full time employees at April 2005 of £431.20 (ONS, 2005). Hours of lost work for parents were taken from the studies described in the previous subsections. For individuals with ASD we used research carried out for the National Autistic Society by Barnard *et al,* (2001) that reported that 12% of individuals with high-functioning ASD or Asperger's had full-time jobs. We assumed that all adults with low-functioning ASD were not in open employment. Again we used the average weekly wage of all full time employees to estimate annual lost productivity costs. These costs are £19,785 for adults with HF autism and £22,383 for those with LF autism.

We were not able to obtain measures of time spent by parents or other family members providing 'informal' (unpaid) care or support for their relative with ASD. Not enough of the datasets that we were able to access had collected this information. We have therefore been forced to assume a zero cost for informal care, both for children and for adults.

Lifetime costs: As well as estimating the costs of supporting all individuals with autism in the UK in a single year, we also sought to estimate the lifetime cost of autism. This was calculated by combining costs for different age groups with life expectancy estimates taken from the Office of National Statistics, Interim Life Tables for the United Kingdom, for the years 2003-2005.

Cost aggregation

The final stage was to pull these various data together – using prevalence rates applied to UK population figures to calculate numbers of people with ASD in groups distinguished by age and level of functioning; then estimating the distribution of those people across accommodation settings (living arrangements); and then attaching a cost to each person (to cover services received that are funded by the state, family resources committed to other services and expenses and lost employment).

We also examined the sensitivity of the estimates to some of the key assumptions made by varying prevalence rates, functioning rates, accommodation proportions and unit costs, although we do not report full details here.

Results

Numbers of people with ASD and functioning level

Applying the 'base case' prevalence rate of 1% and the assumed split between high- and low-functioning ASD of 45:55 to 2005 mid-year UK population figures from the Office of National Statistics gives us the estimated numbers of people with ASD in the UK in Table 1. We assume that 10% of children aged 0-3 with ASD have actually been given a diagnosis by that age, but that for all other age groups the prevalence is 1% of the total population.

Table 1. Estimated prevalence of people with ASD by level of functioning

Age-functioning group	Prevalence per 10,000 population	Number of people with ASD in UK	Mid-year population in UK, 2005
Pre-school (0-3) – high functioning	4.5	1,243	2,763,300
Pre-school (0-3) – low functioning	5.5	1,520	
Primary school (4-11) – high functioning	45	25,675	5,705,600
Primary school (4-11) – low functioning	55	31,381	
Secondary school (12-17) – high functioning	45	21,239	4,719,700
Secondary school (12-17) – low functioning	55	25,958	
Adults (18 years and over) – high functioning	45	194,737	43,275,000
Adults (18 years and over) – low functioning	55	238,013	
Total, all ages and functioning levels		**539,766**	**56,463,600**

We therefore estimate that there are approximately 540,000 people with ASD in the UK: approximately 433,000 adults (aged 18 and over) and 107,000 children and adolescents. As noted earlier, we are assuming that 55% of these people have an IQ below 70.

Place of residence

The estimated distribution of places of residence for children is given in Table 2 by level of functioning, based upon the sources and assumptions set out in the methods section. There are 1,333 children with ASD estimated to be in residential or foster care placements across the UK; all others are living with their families in private households.

Table 2. Places of residence for children with ASD by level of functioning

Age-functioning group	Living in private households with family	Living in foster and residential placements	Total number of children in UK with ASD
Pre-school (0-3) – high functioning	1,243	0	1,243
Pre-school (0-3) – low functioning	1,467	53	1,520
Primary school (4-11) – high functioning	25,675	0	25,675
Primary school (4-11) – low functioning	30,981	400	31,381
Secondary school (12-17) – high functioning	21,239	0	21,239
Secondary school (12-17) – low functioning	25,078	880	25,958
Total, all ages and functioning levels	**105,683**	**1,333**	**107,016**

For adults, our estimates of the numbers of people with ASD in different types of accommodation are given in Table 3, again using the methods set out earlier. We should emphasise again the difficulty of finding accurate statistics for these living arrangements. We estimate that 154,000 adults with high-functioning ASD are living in private households, almost 10,000 in supported accommodation ('Supporting People' settings) and the other 31,000 in residential care. For low-functioning adults with ASD we estimate that 74,000 are living in private households with parents or other relatives, just under 5,000 in private households alone and a similar number in private households with a partner. Another 17,000 adults with low-functioning ASD are in Supporting People settings, 124,000 in residential care accommodation, and 14,000 in hospital.

Table 3. Places of residence for adults with ASD by level of functioning

Place of residence	High functioning	Low functioning
Private household – with parents	153,842	73,784
Private household – with other relatives		
Private household – alone		4,760
Private household – with partner		4,760
Supporting People accommodation	9,737	16,661
Residential care	31,158	123,767
Hospital	0	14,281
Total, all accommodation types	**194,737**	**238,013**

Service use and cost patterns

Data on service use patterns were drawn from our pooled datasets for children and adults.

Children: Data on 143 children (of which 16 were followed up from a previous study) and 93 adults with ASD were extracted from the datasets described earlier. The assessment of autism or PDD had been obtained using a variety of tests and instruments in the original studies. Gender was recorded in all studies and the male/female ratio varied from 3:1 to 13:1. In the sample of children with autism, ages ranged from 3 to 16, with a mean of 10.28 years (standard deviation 3.173), and a median age of 10.

In Table 4 we summarise the average cost per child with low-functioning ASD, whether living with their families or living in a residential or foster care placement. Note that all of these are averages and there will be some individuals with costs very much lower and some with costs very much higher than these mean values. Costs are organised under a number of different service and support heads (in this report we do not discuss patterns of service use but will return to these findings in a later paper). We also include family expenses and imputed costs of lost employment for parents, where appropriate.

Table 4. Average annual cost per child with low-functioning ASD (£, 2005/06 prices)

	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	15,600	22,464	31,928	0	0	0
Hospital services	0	862	1,587	0	862	1,587
Other health & social services	585	6,908	400	585	6,908	400
Respite care	0	0	0	0	2,826	3,684
Special education	0	9,142	27,609	0	9,142	27,609
Education support	0	1,184	997	0	1,184	997
Treatments	0	18	15	0	18	15
Help from voluntary organisations	0	0	0	0	843	96
Benefits	0	0	0	3,757	4,000	4,000
Lost employment (parents)	0	0	0	0	2,086	2,086
Total annual cost (excluding benefits)	**16,185**	**40,578**	**62,536**	**585**	**23,869**	**36,474**
Total annual cost (including benefits)	**16,185**	**40,578**	**62,536**	**4,342**	**27,869**	**40,474**

The table distinguishes children in the three different age groups that we are using throughout this report. The annual costs for children with low-functioning ASD who are living in residential or foster placements are estimated to be £16,185 (if aged 0-3), £40,578 (aged 4-11) and £62,536 (aged 12-17). For the two older age groups the largest contributors to these totals are the care placements themselves, and special education. It is possible, given the availability of data to us, that residential special school costs may be underestimated in our overall calculations.

Costs for children with low-functioning ASD who live with families are much lower: £585 (if aged 0-3), £23,869 (aged 4-11) and £36,474 (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).

In Table 5 we summarise the average cost per child with high-functioning ASD, which ranges from £1,214 to £21,090 per annum. Again, special education is a major element of the total.

Table 5. Average annual cost per child with high-functioning ASD (£, 2005/06 prices)

	Living in private households with family		
	Ages 0-3	**Ages 4-11**	**Ages 12-17**
Hospital services	0	777	777
Other health and social services	1,214	1,214	1,214
Respite care	0	6,510	6,510
Special education	0	11,680	11,680
Education support	0	545	545
Treatments	0	148	148
Help from voluntary organisations	0	0	0
Benefits	469	469	469
Lost employment (parents)	0	216	216
Total annual cost (excluding benefits)	**1,214**	**21,090**	**21,090**
Total annual cost (including benefits)	**1,683**	**21,559**	**21,559**

Expenditure on social security/welfare benefits could partly double-count the costs of lost employment for parents, which is why we provide two totals in tables 4 and 5, with and without adding in the benefit figures.

Adults: The estimated annual costs for adults with high- and low-functioning ASD are presented in Table 6, again distinguishing the main service and support heads. Imputed costs for lost employment are now included for both the individuals with ASD and for parents, where these are appropriate. Costs are arranged by place of residence.

Table 6. Average annual cost per adult with ASD (£, 2005/06 prices)

	Adults with high-functioning ASD			Adults with low-functioning ASD			
	Private household	Supporting People	Residential care	Private household	Supporting People	Residential care	Hospital
Accommodation	1,488	59,022	61,734	0	59,022	61,734	0
Hospital services	777	777	777	87	150	34	75,480
Other health & social services	486	486	486	707	468	579	0
Respite care	0	0	0	1,536	0	0	0
Day services	2,226	2,226	2,226	3,752	3,623	829	0
Adult education	2,886	2,886	2,886	1,435	851	3,316	0
Employment support	0	0	0	504	1,093	0	0
Treatments	148	148	148	62	62	62	0
Family expenses	1,891	0	0	2,177	0	0	0
Lost employment (parents)	3,684	0	0	3,684	0	0	0
Subtotal	**13,076**	**64,918**	**67,514**	**14,124**	**65,269**	**66,554**	**75,480**
Lost employment (person with ASD)	19,785	19,785	19,785	22,383	22,383	22,383	22,383
Total (excl. benefits)	**32,681**	**84,703**	**87,299**	**36,507**	**87,652**	**88,937**	**97,863**
Benefits	0	0	0	6703	4,320	4,320	925
Total (inc. benefits)	**32,681**	**84,703**	**87,299**	**43,210**	**91,972**	**93,257**	**98,788**

For an adult with high-functioning ASD we estimate the annual cost of living in a private household (with or without family – we are unable to separate the two with our cost data) to be £32,681. A sizeable part of this (£19,785) is the imputed cost of lost employment for the individual with ASD (and hence also lost productivity to the economy). Some 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 (£84,703 and £87,299 per annum respectively), and the proportion attributable to lost employment is lower. Not surprisingly, 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, we calculate mean annual costs (excluding benefits but including lost employment) to be £36,507 for those living in private households, £87,652 in Supporting People settings, £88,937 in residential care and £97,863 for those living long-term in hospital. Again, remember that all of these figures are averages, and therefore hide a wide inter-individual range. For people in private households the largest service cost elements are associated with day care, respite services, and adult education. For people in Supporting People settings and residential care, the largest cost element is accommodation itself (and again includes the costs of staff employed there). High cost service elements are associated with day care and employment support.

Table 7. Aggregate national annual costs for children with ASD (£ million, 2005/06 prices)

	Number of children	Average cost (£)	Total cost (£ million)
Children with low-functioning ASD living with families			
Ages 0 – 3	1,467	585	0.86
Ages 4 – 11	30,981	23,869	739.49
Ages 12 – 17	25,078	36,474	914.69
Children with low-functioning ASD in residential/foster care			
Ages 0 – 3	53	16,185	0.86
Ages 4 – 11	400	40,578	16.23
Ages 12 – 17	880	62,536	55.03
Children with high-functioning ASD living with families			
Ages 0 – 3	1,243	1,214	1.51
Ages 4 – 11	25,675	21,090	541.49
Ages 12 – 17	21,239	21,090	447.93
All ages and levels of functioning		**107,016**	**2,718.08**

Aggregate national cost

Multiplying these calculated mean annual costs by the estimated prevalence rates (by type of accommodation, level of functioning and age group) gives the total national cost figures in Tables 7 and 9, as well as the component national figures in Tables 8 and 10.

Children: The aggregate national costs of supporting children with ASD are estimated to be £2.7 billion (Table 7). Of this total, £1.7 billion is accounted for by children with low-functioning ASD living with their families, £72 million by children with low-functioning ASD living in residential or foster placements, and £1 billion by children with high-functioning ASD living with their families. Re-summing the figures by age group, we estimate that only a small cost is accounted for by pre-school children (£3 million), £1.3 billion by those aged 4-11, and £1.4 billion by those aged 12-17.

Table 8. Component national annual costs for children with ASD (£ million, 2005/06 prices)

	Service costs	Family costs (expenses, lost employment)	Total cost excluding benefits	Benefits
Children with low-functioning ASD living with families				
Ages 0 – 3	0.86	0	0.86	5.51
Ages 4 – 11	674.86	64.63	739.49	123.92
Ages 12 – 17	862.38	52.31	914.69	100.31
Children with low-functioning ASD in residential/foster care				
Ages 0 – 3	0.86	0	0.86	0
Ages 4 – 11	16.23	0	16.23	0
Ages 12 – 17	55.03	0	55.03	0
Children with high-functioning ASD living with families				
Ages 0 – 3	1.51	0	1.51	0.58
Ages 4 – 11	535.94	5.55	541.49	12.04
Ages 12 – 17	443.34	4.59	447.93	9.96
All ages & functioning levels	**2,591.01**	**127.08**	**2,718.09**	**252.32**

Across all age groups and both levels of functioning, 95% of the total national cost for children (which is £2.7 billion excluding benefits) is accounted for by services, and 5% by family expenses (Table 8). Benefit payments add only a small amount to the sum of these two groups (£252 million; 9% of the total).

Adults: The aggregate costs for adults sum to £25 billion. Almost two-thirds of this total, £17 billion (66.4%) is accounted for by the costs of supporting low-functioning adults (including lost employment costs) (Table 9). These sums exclude benefit payments.

Table 9. Aggregate national annual costs for adults with ASD (£ million, 2005/06 prices)

	Number of adults	Average cost (£)	Total cost (£ million)
Adults with low-functioning ASD			
Living in private households	83,304	36,507	3,041.12
Living in Supporting People accommodation	16,661	87,652	1,460.37
Living in residential care	123,767	88,937	11,007.47
Living in hospital	14,281	97,863	1,397.58
Adults with high-functioning ASD			
Living in private households	153,842	32,681	5,027.71
Living in Supporting People accommodation	9,737	84,703	824.75
Living in residential care	31,158	87,299	2,720.06
All levels of functioning and places of residence	**432,750**		**25,479.06**

If we again leave benefit payments out of the calculation, 59% of the total national cost is accounted for by services, 36% by lost employment for the individual with ASD, and the remaining 5% by family expenses (Table 10). Benefit payments again amount to a relatively small sum in comparison to these other costs.

Lifetime costs

Lifetime costs for autism were derived by multiplying the average costs by the number of years lived in each age group. The lifetime cost for someone with high-functioning autism, taking a weighted average across different living arrangements, is estimated at £2.9 million (Table 11). For someone with low-functioning autism we estimate the lifetime cost to be 59% higher at £4.7 million. These are both conservative estimates that do not include, for example, the costs of informal care by families.

Table 10. Component national annual costs for adults with ASD (£ million, 2005/06 prices)

	Service costs	Lost employment (individual)	Family (expenses, lost employment)	Total cost *excluding* benefits	Benefits
Adults with low-functioning ASD					
Living in private households	688.34	1,864.59	488.24	3,041.17	558.39
Living in Supporting People acc	1,087.45	372.92	0	1,460.37	71.98
Living in residential care	8,237.19	2,770.28	0	11,007.47	534.67
Living in hospital	1,077.93	319.65	0	1,397.58	13.21
Adults with high-functioning ASD					
Living in private households	1,153.97	3,043.76	857.67	5,027.71	0
Living in Supporting People acc	632.11	192.65	0	824.75	0
Living in residential care	2,103.60	616.46	0	2,720.06	0
All functioning levels & accommodation	**14,980.59**	**9,180.31**	**1,345.91**	**25,479.06**	**1,178.25**

Table 11: Lifetime costs of ASD (£, 2005/06 prices)

Age group	Number of years	Low-functioning ASD costs		High-functioning ASD	
		Average annual cost	Total cost per person	Average annual cost	Total cost per person
Ages 0-3	4	1,129	4,516	1,214	4,856
Ages 4-11	8	24,082	192,656	21,090	168,720
Ages 12-17	6	37,358	224,148	21,090	126,540
Ages 18+	60	71,032	4,261,920	44,021	2,641,260
Lifetime cost			**4,683,240**		**2,941,376**

Discussion

In this report we have pulled together, with some considerable difficulty given the paucity of available data, information from a wide array of sources. Using UK-specific and international evidence on prevalence, levels of functioning, places of accommodation, patterns of service use, costs, unemployment rates and life expectancy, we have produced the most detailed, disaggregated and up-to-date estimate of the cost of autistic spectrum disorders in the UK. In terms of detail and coverage we have been able to move some distance beyond the estimates by Järbrink and Knapp, (2001).

Relevance of these new estimates

Why are our new cost estimates relevant?

Public sector impact: First, we have been able to estimate the costs of supporting children and adults with autism that fall to the public sector, whether to the health system, social care agencies, education or housing. This disaggregation of costs, although not discussed in detail in this report, clearly demonstrates the breadth of impact of a set of disorders as complex and heterogeneous as ASD.

Of course, every individual will make some use of health services, and many people will use other services too. But people with ASD do appear to be high users. An American study by Croen and colleagues (2006) compared the utilisation and costs of health care services for a non-profit health insurance agency serving more than 3 million people in northern California. They found that average annual costs were 45% higher for children with ASD compared with children without ASD.

Family impacts: Second, we have also identified costs to families. A high proportion of the overall costs of ASD falls to families, whether in terms of out-of-pocket expenses, lost employment opportunities and income or (although not costed here) time spent providing informal care, commonly with considerable psychological impacts. The high costs accruing to families were consistent with our own previous findings for children with behavioural disorders (Romeo *et al*, 2006; Knapp *et al*, 1999), which also found that families bore a large proportion of the caring activities. This may be partly because about 30% of children with autism have a clinically recognisable emotional or anxiety disorder, or an additional diagnosis of conduct disorder (Green, 2005). A higher proportion of families with autism receive welfare benefits than for families of children with conduct and emotional disorders. This reflects the impact that caring imposes on families, not only because of the behaviour patterns of the child, but often their intellectual and physical disabilities as well (Green, 2005). The question raised by these high costs is whether this burden – economic and otherwise – is reasonable for a society to expect of families.

Early intervention pay-offs: Third, the high costs associated with supporting adults with ASD warrant attention because there ought, potentially, to be some scope for reducing them by making more widely available those early interventions that have been shown to alter patterns of behaviour.

Those interventions could divert many people from care pathways that are expensive, as this report shows, and improve the quality of life of those individuals and their families.

The figures in this report do not provide an economic case for early intervention, but they do emphasise the importance of addressing just that question. The study by Bebbington and Beecham (2007) of social services support for children with autism suggests expenditure tends to be high when compared to that for other disabled children. Among children with autism, costs for children with additional behaviour and communication problems are particularly high. Moreover, children over the age of 11 years are more likely to use the higher cost residential facilities than foster care, with children under 10 being more likely to use foster care. If early intervention improved behaviour it may be that savings could be made in the costs of support as children with autism age through the care system.

Lifetime costs: Our estimates of lifetime costs remain high and, again, may support arguments for effective early intervention to help ameliorate the impacts of autism and thus potentially reduce the intensity of support needed in adult life. Our estimate of £4.6 million for the lifetime cost of someone with low-functioning ASD is higher than previously estimated by Järbrink and Knapp (2001), partly because we have used a more recent price base but mainly because we have been able to be more comprehensive in our measurement of the various economic impacts. In a study of age-specific and lifetime incremental societal costs in the United States, Ganz (2007) estimated the lifetime cost of autism as $3.2 million for an individual, and the overall national cost to be $35 billion for a cohort of people with autism.59% of the cost resulted from lost productivity for the individual or family because of missed time at work, reduced hours, changing to a lower paid or more flexible job, or leaving the work force.

The fourth reason why these new cost figures are important is, therefore, because we have been able to include estimates of the impact on the UK economy through lost productivity. At a time when the government is emphasising the need for higher rates of economic activity, and in particular is trying to support people with disabilities and long-term conditions to move into paid employment, the high costs of lost employment/productivity for people with ASD and their families stand out. Very few people with autism are in employment. This is not surprising as there is little or no support to get people with autism into work (Howlin, 2004). Another explanation lies in lower educational attainment: Dearden and colleagues, (2004) estimated an average return of 27% for those completing some form of higher education compared to anything less, i.e. 'marginal learners', a group into which some people with ASD will fall as they may be educationally able to complete such courses but are held back by the various access barriers they face. Of course, it will be no easy task to achieve higher employment rates among people with ASD, and it will certainly require careful and probably costly support arrangements.

These new figures give us an up-to-date indication of the overall economic impact of ASD in the UK. The total estimated UK cost of £28 billion averages out at around £500 each year for every man, woman and child in the country. These figures, however, only tell us what is spent (or lost) today and not what ought to be spent.

The diversity of sectors on which autism has an impact shows there is clearly a need to coordinate action across different parts of government and society more generally. There is also a need to improve our knowledge on the cost and cost-effectiveness of various supports for children and adults to ensure that decision makers have a stronger evidence base when deciding how best to allocate and spend resources on autism.

References

Aitken K (2001) Autism increase, New Scientist, 12-3-2001.

Atladottir HO, Parner ET, Schendel D, Dalsgaard S, Toomsen PH, & Thorsen P (2007). Variations in incidence of neurodevelopmental disorders with season of birth. Epidemiology, 18(2).

Baird G, Simonoff E, Pickles A, Chandler S, Loucas T, Meldrum D, Charman T (2006) Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). Lancet, 368, 210-215.

Barnard J, Harvey V, Potter D, Prior A (2001) Ignored or ineligible? The reality for adults with autism spectrum disorders, National Autistics Society, London.

Bebbington A, Beecham J (2007) Social services support and expenditure for children with autism. Autism, 11(1), 43-61.

Beecham J, Knapp M (2001) Costing psychiatric interventions, in Thornicroft G (ed) Measuring Mental Health Needs, Gaskell, London.

Bromley, J., Hare, D. J., Davison, K., & Emerson, E (2004) Mothers supporting children with autistic spectrum disorders: social support, mental health status and satisfaction with services. Autism, 8 (4), 409-423.

Centre for Disease Control and Prevention (2007) Prevalence of Autism Spectrum Disorders --- Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, MMWR Surveillance Summaries. February 9, 2007 / 56(SS01); 12-28. http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5601a2.htm

Chadwick O, Taylor E, Bernard S (1998) The prevention of behaviour disorders in children with severe learning disabilities. Final Report to the NHS Executive. Institute of Psychiatry.

Chakrabarti S & Fombonne E (2005) Pervasive developmental disorders in preschool children: confirmation of high prevalence. American Journal of Psychiatry, 162, 1133-1141.

Cooper, S.A., Morrison, J., Melville, C., Finlayson, J., Allan, L., Martin, G., & Robinson, N (2006) Improving the health of people with intellectual disabilities: outcomes of a health screening programme after 1 year. Journal of Intellectual Disability Research, 50(9), 667-677.

Croen L, Najjar DV, Ray T, Lotspeich L, Bernal P (2006) A comparison of health care utilization and costs of children with and without autism spectrum disorders in a large group-model health plan. Pediatrics, 118(4).

Dearden L, McGranahan L, Sianesi B (2004) Returns to education for the 'Marginal Learner': evidence from the BCS70, Discussion Paper 45, Centre for the Economics of Education, London School of Economics, London.

Emerson E, Mallam S, Davies I, Spencer K (2005) Adults with learning difficulties in England 2003/4, Office of National Statistics and NHS Health and Social Care Information Centre, London.

Fombonne E (2003) Epidemiological surveys of autism and other pervasive developmental disorders: an update. Journal of Autism and Developmental Disorders, 33 (4).

Fombonne, E (2005) Epidemiology of autistic disorder and other pervasive developmental disorders. Journal of Clinical Psychiatry, 66 (Supplement 10), 3-8.

Filipek PA, Accardo PJ, Baranek GT, Cook Jr.EH, Dawson G, Gordon B, Gravel JS, Johnson CP, Johnson CP, , K. R., Levy SE, Minshew NJ, Prizant BM, Rapin I, Rogers SJ, Stone WL, Teplin S, Tuchman RF, & Volkmar FR (1999) The screening and diagnosis of autism spectrum disorders. Journal of Autism and Developmental Disorders, 29(2).

Ganz ML (2007) The lifetime distribution of the incremental societal costs of autism. Archive Paediatric Adolescents Medicine, 161.

Ghaziuddin M, Weidmer-Mikhail E, Ghaziuddin N (1998) Comorbidity of asperger syndrome: a preliminary report. Journal of Intellectual Disability Research, 42(4).

Greco V, Sloper P, Webb R, Beecham J (2005) An exploration of different models of multi-agency partnerships in key worker services for disabled children: effectiveness and costs. Department for Education and Skills.

Green H, McGinnity A, Meltzer H, Ford T, Goodman R (2005) Mental health of children and young people in Great Britain, 2004. Office of National Statistics.

Howlin P, Goode S, Hutton J, Rutter M (2004a) Adult outcomes for children with autism. Journal of Child Psychology and Psychiatry 45(2), 212-229.

Howlin P, Alcock J, Burkin C (2004b) An 8 year follow-up of a specialist support employment service for high-ability adults with autism or asperger syndrome. Autism 9(5).

Howlin P (2000) Outcome in adult life for more able individuals with autism and asperger syndrome Autism, 4(1).

Isager T, Mouridsen SE, Rich B (1999) Mortality and causes of death in pervasive developmental disorders. Autism, 3(1) 7-16.

Jacobs B, Beecham J, Briskman J, Tobias C, Green J, Kroll L, Dunn G, Baird L (2004) Two and a half thousand hours: the children and young people inpatient evaluation study (CHYPIE) into process and outcome of inpatient child and adolescent psychiatry. Department of Health.

Järbrink K, Fombonne E, & Knapp M (2003). Measuring the parental, service and cost impacts of children with autistic spectrum disorder: a pilot study, Journal of Autism and Developmental Disorders, 33(4).

Järbrink K & Knapp M (2001) The economic impact of autism in Britain, Autism, 5(1) 7-22.

Knapp M., Scott S., Davies J (1999) The cost of antisocial behaviour in younger children. Clinical Child Psychology and Psychiatry. 4 457-473.

Lawton G (2005). The autism epidemic that never was. New Scientist [2512]. 13-8-2005.

Le Page M (2001). False alarm. New Scientist [2278]. 17-2-2001.

Leslie DL & Martin A (2007) Health care expenditure associated with autism spectrum disorder. Archive Paediatric Adolescents Medicine, 161.

Lockyer L & Rutter M (1969). A Five to Fifteen Year Follow-up Study of Infantile Psychosis: III. Psychological aspects. British Journal of Psychiatry, 115. 865-882.

Office of National Statistics (2005) First release: 2005 annual survey of hours and earnings. Office of National Statistics. 2005. 13-2-0007.

Office of National Statistics (2005) Interim life tables, United Kingdom. http://www.statistics.gov.uk/downloads/theme_population/Interim_Life/ILTUK0305.xls#'2003-05'!A1[accessed 19/12/06].

Perry J, Romeo R, Meek A, Felce D, Robertson J, Emerson E, Knapp M. Outcomes and costs of community living: Semi-independent living and fully staffed group homes (2007) American Journal on Mental Retardation in press.

Piven J and Palmer C, (1999) Psychiatric disorder and the broad spectrum autism phenotype: evidence from a family study of multiple incidence autism families. American Journal of Psychiatry 156 (4), 557-63.

Robertson J, Emerson E, Hatton C, Elliott J, McIntosh B, Swift P, Krijnen-Kemp E, Towers C, Romeo R, Knapp MRJ, Sanderson H, Routledge M, Oakes P, & Joyce T (2005) The Impact of Person Centred Planning, Department of Health, London.

Romeo R, Knapp M, Scott S (2006) Economic cost of severe antisocial behaviour in children and who pays. British Journal of Psychiatry,188, 547-553.

Rutter M, Greenfeld D, & Lockyer L (1967) A five to fifteen year follow-up of infantile psychosis II social and behavioural outcome. British Journal of Psychiatry, 113, 1183-1189.

Rutter M & Lockyer L (1967) A five to fifteen year follow-up of infantile psychosis I description of the sample. British Journal of Psychiatry, 113,1183-1189.

Ryde-Brant B (1990) Anxiety and depression in mothers of children with psychotic disorders and mental retardation. British Journal of Psychiatry, 156,118-121.

Sander JI & Morgan SB (1997) Family stress and adjustment as perceived by parents of children with autism or down syndrome: implications for intervention. Child & Family Behavior Therapy. 19(4) 15-32.

Smith B, Chung M, & Vostanis P (1994) The path to care in autism: is it better now? Journal of Autism and Developmental Disorders, 5.

Wing L(1993). The definition and prevalence of autism: a review. European Child and Adolescent Psychiatry, 2(2).

Foundation for People
with Learning Disabilities

About the Foundation for People with Learning Disabilities

We promote the rights, quality of life and opportunities of people with learning disabilities and their families. We do this by working with people with learning disabilities, their families and those who support them to:

- do research and develop projects that promote social inclusion and citizenship
- support local communities and services to include people with learning disabilities
- make practical improvements in services for people with learning disabilities
- spread knowledge and information

If you would like to find out more about our work, please contact us:

Foundation for People with Learning Disabilities
Sea Containers House
20 Upper Ground
London SE1 9QB
020 7803 1100

www.learningdisabilities.org.uk

The Foundation for People with Learning Disabilities is part of the Mental Health Foundation, registered charity number 801130.

ISBN 978-1-906162-05-4