

The economic consequences of autism in the UK

Executive research and policy briefing from the
Foundation for People with Learning Disabilities

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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. However little was known about the economic consequences of autism until the late 1990's when the Foundation for People with Learning Disabilities, with funding from the Shirley Foundation, commissioned Professor Martin Knapp & Krister Jarbrink of the Centre for the Economics of Mental Health to estimate the costs of autism spectrum disorders (ASDs) in the UKⁱ.

That groundbreaking work has now been updated by Professor Knapp, Renee Romeo and Jennifer Beecham to take advantage of more detailed data that is availableⁱⁱ, again with funding from the Shirley Foundation. This means that in addition to the costs associated with health and social care support for people with ASDs, the new estimates include a broader span of public sector expenditure, such as education and housing. These are placed alongside estimates of the out-of-pocket expenses incurred by families and the income and employment opportunities lost by individuals with ASDs and their families.

Key findings from the research

- There are approximately 540,000 people with ASDs in the UK, of whom 433,000 are adults (aged 18 and over) and 107,000 are children.
- It is estimated that 55% of people with an ASD also have a learning disability.
- The aggregate cost of supporting people with ASDs in the UK is £27.5 billion annually.
- Of this, 59% is accounted for by services, 36% by lost employment for the individual with an ASD, their families and other carers, and the remainder by family expenses.
- The lifetime cost for someone with an ASD and a learning disability is estimated to be £4.7 million and £2.9 million for someone with a 'high-functioning' ASD.
- Average annual costs for children with an ASD and a learning disability who are living in residential or foster placements range from £16,185 to £62,536. Costs were considerably lower if these children live with their families.
- Average annual costs for children with a high-functioning ASD range from £1,214 to £21,090.

- Average annual costs for adults with an ASD and a learning disability range from £36,507 to £97,863.
- Average annual costs for an adult with a high-functioning ASD range from £32,681 to £87,299.

The research has important implications for policymakers, public services and families by demonstrating the breadth of public services used by people with ASD, the high proportion of the overall cost that falls to families, the lost productivity to the UK economy, and the potential benefits that might accrue from investment in appropriate interventions and supports to people with ASDs and their families.

Background

Autistic spectrum disorders are more common than was previously estimated, although there is considerable debate about the extent to which this represents a real underlying increase in prevalence rather than changes in diagnostic criteria or improvements in identification. What is agreed, however, is that there is much greater public awareness of autism today than ever before.

The impact of ASDs upon the health, economic and social wellbeing of individuals, their families and the rest of society varies from individual to individual depending on a variety of factors, including age, level of cognition and ability to live independently. While interventions and services currently used to support people with ASDs all impose costs, either to the state or to a charity or to the families of people with ASDs, their availability remains low and unevenly spread, so that the burdens and stresses experienced by families tend to persist. As well as bearing the practical burdens and perhaps psychological stresses of having a child with an 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.

The research

The aim of the research 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 research relied heavily on the most recent estimates available from published research, official statistics and advice from experts in the field to determine the prevalence and distribution of ASDs within the general population.

Prevalence estimates

For the calculations a prevalence estimate of 1% across all ages was used, which is slightly lower than the figure from the most recent study, but was the figure recommended for an “all-ages” approach by Dr Tony Charman. On this basis, it is estimated that there are approximately 540,000 people with ASDs in the UK.

Level of functioning and age

Given the heterogeneity of needs of people with ASDs, it was necessary to distinguish people with ‘high-functioning’ autism (i.e. with an IQ equal to or above 70) from people with an ASD and a learning disability (i.e. with an IQ below 70). The base assumption used was that 55% of this population has a learning disability and 45% has high-functioning autism. The population was also classified by age: pre-school children (0-3), primary school children (4-11), secondary school children (12-17) and adults (18 years and above). It is estimated that there are approximately 433,000 adults and 107,000 children with ASD in the UK.

Place of residence

Based on published research and official statistics, it was assumed that all children with high-functioning autism live with their parents, as do the vast majority of children with an ASD and a learning disability, save for the small number (approximately 1,333 or 1.25%) who live in residential or foster placements.

Accommodation arrangements for adults had to be estimated in the absence of any directly collected data on it. Of adults with high-functioning autism, 79% live in private residences with parents or other relatives, 5% in Supporting People accommodation, 16% in residential care and none in hospital. Of those adults with an ASD and a learning disability, 31% live in private residences, 2% in private house alone, 2% in private households with a partner, 7% in Supporting People accommodation, 52% in residential care and 6% in hospital.

Costs

A number of different costs were analysed, including those for health, social care, education, housing and leisure

services, but only where they related to an individual’s ASD. For example, the costs of special education were included, but not for mainstream education. The costs to families and other carers of hours of support provided, out-of-pocket expenses, lost productivity from unemployment or disrupted employment were also included. Previous research has tended not to address the issue of lost productivity for people with moderate or severe learning disabilities. However, the emphasis on choice and opportunity in Government policy suggested that inability to work has an opportunity cost both to an individual and to society so that it is completely appropriate to include these costs in this study.

Datasets used

A pooled dataset on children with ASD was drawn from four English studies of children with intellectual disabilities and/or mental health problems. From each of these datasets the information on all of those children with autism or those diagnosed as having a pervasive developmental disorder (PDD) was extracted. The data on adults with ASD were obtained from five studies on adults with intellectual disabilities.

Results

1. Average annual costs of supporting children

The annual costs for children with an ASD and a learning disability 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. For children with an ASD and a learning disability who live with families, the costs 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).

The annual costs for children with a high-functioning ASD are £1,683 (if aged 0-3), £21,559 (aged 4-11) and £21,559 (aged 12-17). Again, special education is a major element of the total.

2. Average annual costs of supporting adults

For an adult with high-functioning ASD the annual cost of living in a private household (with or without family) is estimated 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). 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 this includes the costs of support staff.

For adults with an ASD and a learning disability, the mean annual costs (excluding benefits but including lost employment) are calculated 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. 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.

3. Aggregate national costs of supporting children

The aggregate national costs of supporting children with ASD are estimated to be £2.7 billion per annum, of which £1.7 billion is accounted for by children with ASDs and learning disabilities living with their families, £72 million by children with ASDs and learning disabilities living in residential or foster placements, and £1 billion by children with high-functioning ASD living with their families. By age group, it is estimated 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. Across all age groups and levels of functioning, 95% of the total national cost for children is accounted for by services, and 5% by family expenses.

4. Aggregate national costs of supporting adults

The aggregate costs for adults sum to £25 billion per annum. Almost two-thirds of this total, £17 billion (66.4%) relates to the costs of supporting those adults with an additional learning disability. Excluding benefit payments (which account for a very small amount of the total) from 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.

5. Lifetime costs

The lifetime cost for someone with high-functioning autism, taking a weighted average across different living arrangements, is estimated at £2.9 million. For someone who also has a learning disability, the lifetime cost is calculated 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.

Implications

The research has a number of implications for policymakers, the providers of public services and the families of people with ASD.

Firstly, people with ASD appear to be high users of public services and this research demonstrates, for the first time, the breadth of the impact of this complex set of disorders.

Secondly, a high proportion of the overall cost of ASD falls to families, whether in terms of out-of-pocket expenses, lost employment opportunities and income or time spent providing informal care, commonly with considerable psychological impacts. The question raised by these high costs is whether this burden – economic and otherwise – is reasonable for a society to expect of families.

Thirdly, 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. Investment in support to families may prevent children being placed in expensive residential accommodation away from home.

Fourthly, the research sheds light on the impact on the UK economy through lost productivity. At a time when the government is emphasizing 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 and will need specialised support to find and remain in work.

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. The time now seems right to develop a national strategy on autism.

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Further information

To obtain a copy of the full report, please call the Foundation for People with Learning Disabilities on 020 7803 1100 or email us at fpld@fpld.org.uk

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- i See Mental Health Foundation Updates, Vol 1, No 17, 'The Cost of Autistic Spectrum Disorder'.
- ii The full report can be downloaded from the website of the Foundation for People with Learning Disabilities www.learningdisabilities.org.uk