

# *The Cost of Autistic Spectrum Disorder*

## SUMMARY

In order to evaluate the benefits of new services or interventions for children and adults with autism, it is important to know the economic and social consequences of non-intervention. Very little information exists on the economic costs of autism - to society, to families and carers, and to people with autism and Asperger's Syndrome.

**Professor Martin Knapp** and **Krister Jarbrink**, of the Centre for the Economics of Mental Health (CEMH), were commissioned by the Mental Health Foundation, with funding from The Shirley Foundation, to carry out an exploratory study of the costs of autistic spectrum disorders. The study was based on a review of published international literature, and on analysis of current data which includes people with autism.

The key findings of the research were as follows:

- The annual total cost of autistic disorder in the UK is at least **£1 billion**;
- The average additional lifetime cost resulting from autism and associated learning disabilities is estimated to be **£2,940,538** per person;
- The greatest costs are for living support (70%) and day activities (14%); much less is spent on education (7%). Evidence suggests that even moderate increases in educational provision could potentially result in major savings in later living costs;
- The economic consequences to parents of having an autistic child living at home include an annual loss of earnings estimated as at least 1/6<sup>th</sup> of the average disposable income;
- Further information is needed on the costs to families of having a child with autism, and on the economic costs of high-functioning autism and Asperger's Syndrome.

## BACKGROUND

Autistic spectrum disorders, including autism, high-functioning autism, and Asperger's Syndrome, were first described in the 1940's, but have only recently been clearly defined. The prevalence of autistic disorder appears to be around 5 to 10 per 10,000 children. Asperger's Syndrome is thought to affect 26 to 36 per 10,000 children.

60% of children with typical autism will grow up to be dependent on adults in all aspects of life. Just below 10% of children diagnosed with autism do well in adult life. In between these groups are children whose adult lives are somewhat restricted. Children diagnosed with Asperger's Syndrome tend to do better as adults than children diagnosed with autistic disorder, but they have an increased risk of depression, alcohol problems, and suicide in adolescence.

There has been an increase in the number of children with autism registered as having special needs or registered as disabled, showing an increasing demand for specialist services. New interventions, mainly based on intensive behavioural training, have reported some good short-term results (McEachin J, Smith, T, Lovaas, O.I (1993)). But there is a need for further rigorous evaluation of these methods, and for an evaluation of the economic costs of autism and the costs/ benefits of intervention.

## THE RESEARCH

The aim of this research was to conduct a short-term exploratory study of the costs of autistic spectrum disorder, based on a review of published international literature and on analysis of current data sets which include people with autism. The study examined both *direct costs* of resources used (health, social and educational services, residential care, medication, care management, legal services, travel to treatment) and *indirect costs* of resources lost due to illness (e.g. loss or lack of employment, for the individual with autism and/or their family members).

300 relevant research articles were identified from databases and hand-searching, but only two of these contained any information on costs (both from the US). Three previous studies which had been carried out by CEMH using the Client Service Receipt Inventory provided cost information on children and adults with learning disorders and language delay, respectively. These were useful in estimating the costs of services for children and adults with both low and high functioning autism. Other information was obtained from reports and surveys of autism and other disabilities within the spectrum.

For each service a *unit cost* was estimated. The *frequency* of use was estimated, based on previous studies of people with autistic spectrum disorder. For people with high-functioning autistic spectrum disorder, the frequency of use of non-hospital services was estimated from a study of boys with developmental language disorders. Loss of productivity costs were based on the costs of early-retirement and 'under-employment'.

The study did not include carers' health costs, drug abuse and criminality, or the costs of early intensive behavioural interventions, which were not available to the people from whom data was collected.

## THE FINDINGS

- The **annual** cost for autism/autistic disorder in the UK is at least £1 billion, depending on which prevalence figures are used.
- The average additional **lifetime** cost for an individual with autism and additional learning disability is estimated to be £2,940,538.
- For people with high-functioning autism, the additional lifetime cost is estimated to be £784,785. The additional lifetime cost for people with Asperger's Syndrome is estimated to be £525,070.

- The costs of residential care/living support and supervised day activities account for the majority of the total costs. For example, a conservative estimate of the average costs of residential care for someone with autistic disorder and additional learning disability is £40,000 per year.
- The annual average cost for attending a special residential school is estimated to be £30,000 compared with £10,000 for a special day school. Assuming that 15% of the children with autism/learning disability who receive special education are in residential schools, the annual average cost for special education for children with autism and additional learning disabilities is £13,000.
- More than 75% of children with Asperger's are able to attend mainstream schools, resulting in an average cost for special education of £1,500. 60% of children with high-functioning autism attend special day schools, which cost £10,000 per year, resulting in annual average costs of £8,550.
- Sheltered employment costs for people with autism are low because few people have had access to these schemes: e.g. £448 per annum for people with autistic disorder aged 20-24 and £2,468 for people with Asperger's, who tend to work more hours per week. The unit cost of running a supported employment scheme for people with high-functioning autism and Asperger's has been estimated as £388 per month per client (Mawhood & Howlin 1999).
- Other costs include hospital care, medication, lost productivity, family expenses, loss of parental earnings, social services, hospital services and respite care.

## THE IMPLICATIONS

- The costs for residential care and day activities are considerable. This implies that potentially great savings could be achieved by interventions which increase the possibility of independent living. For example, an early intervention lasting three years, at an annual cost of £25,000, might prove cost-effective if four out of ten recipients or more were subsequently able to manage in sheltered accommodation and employment rather than in residential care.
- More research is needed into the cost-effectiveness of early interventions, and their potential impact on education costs.
- This study has estimated the minimum social costs for autistic disorder, but the economic costs of high-functioning autistic spectrum disorders need further investigation.
- Further research is also needed into the economic and social costs to families of having a child with autism, and their implications for quality of life.

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**References and further reading:**

Jarbrink, K. & Knapp, M. (2000) 'The economic burden of autism in Britain' [The full empirical findings have been submitted to *Autism* to be considered for publication in the journal.]

Mawhood, L. & Howlin, P. (1999) 'The outcome of supported employment schemes for high-functioning adults with autism and Asperger Syndrome' *Autism*, 3, 229-254.

McEachin, J., Smith, T. & Lovaas, O.I. (1993) 'Long-term outcome for children with autism who received early intensive behavioural treatment.' *American Journal on Mental Retardation*, 97, 4, 359-372.

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