

Professor Martin Knapp: Autism Costs



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Autism is often in the news. This past week the Center for Disease Control and Prevention (CDC) in the USA announced new estimates for prevalence: **1 child in every 88 has an autism spectrum disorder**. This is a jump from their previous figures for the US, but actually almost identical to what Gillian Baird and colleagues found in South East England a few years ago in their 2006 *Lancet article*.

In 1998, autism hit the headlines when the *Lancet* published a paper by **Andrew Wakefield** and colleagues that suggested a link between the MMR vaccine and autism. The work and the lead author were later discredited, but not before MMR vaccination rates had fallen steeply, and the number of measles cases had risen.

The autism field is never far from controversy, it seems. One enduring issue is whether the higher prevalence rates uncovered by successive studies in various parts of the world are due to a **genuine underlying increase in the number of people with autism spectrum disorders, or whether the health, education and other systems are just getting better at detecting it**.

I am not going to wade into those choppy waters with an opinion because it could only be poorly informed. But the underlying prevalence rate is vitally important for research currently underway at the **London School of Economics and Political Science (LSE)**.

Counting the costs

With funding from **Autism Speaks**, a leading international charity in the field, we are calculating the overall cost of autism in the UK and in the US. Ariane Buescher, Jeni Beecham and I (all based in **PSSRU** at the LSE) are working with Renee Romeo from **King's College London** to update previous estimates from 2006. (We published **our findings** in the journal *Autism* in 2009). In our new study, we are working closely with David Mandell and Zuleyha Cidav from the University of Pennsylvania School of Medicine who are developing similar figures for the US.

The prevalence rate is the starting point for our calculations. We then look at the age distribution and characteristics of people with autism (in particular whether or not they have intellectual disabilities). We chart their accommodation arrangements (e.g. how many live in special staffed settings or with their families), the services they use (health, education, social care and so on), and the support they get from their families. We are interested in the costs to families too.

Another key component in our calculations is how many people with autism are employed. This is especially important for a range of reasons. One is that autism is a spectrum, and some people are quite disabled by their needs (particularly if they also have intellectual disabilities) while others (especially those with Asperger Syndrome) can be enormously talented. Being out of employment is a social cost, while being *in* employment is a source of income, social networking and so on.

In our project we are calculating the cost of each of these service, accommodation, family and employment impacts. This means we can estimate the average lifetime cost of someone with autism, as well as the total economic impact nationally in a single year.

Hong Kong 'summit'



The costs that we have calculated for the UK were presented at an ‘Autism Summit’ in Hong Kong on 31 March. They are *tentative*, and need to be checked before we submit our work to external review and then for wider publication.

For the UK we conservatively estimate that the lifetime cost for someone with autism and intellectual disability is £1.5 million. For someone with autism but without ID it is about £900,000. At today’s exchange rates, these figures are remarkably similar to those calculated for the US (\$2.3 and \$1.4 million). The overall UK cost of autism is about £34 billion each year. But remember that these are preliminary figures.

Of more relevance is what is contained *within* this figure: high education costs, high costs too if someone with autism is unable to live in the community but needs some form of specialist staffed accommodation. There are also high costs for families, in terms of both income losses (if a parent has to give up work) and out-of-pocket expenses. There is still poor coordination across different agencies and budgets, as the [government’s spending watchdog showed in 2009](#). The previous government’s response was an [adult autism strategy published in March 2010](#).

We are still working on this study. We are going back over our cost estimates to improve and finalise them. And we are starting a new phase of work, again funded by Autism Speaks (and again in collaboration with our University of Pennsylvania colleagues). This new phase will be evaluative, looking to see if there is an economic case for early intervention.

This costing research is one of a clutch of autism studies now underway in PSSRU at LSE. Please get in touch if you would like to know more.

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