Autism costs in Germany: Scarce data

Christian Bachmann, a child and adolescent psychiatrist from Philipps University Marburg, Germany, spent 2 months at PSSRU as a visiting researcher in 2013. During his stay, he created an economic model estimating the societal costs of autism spectrum disorders (ASD) in Germany. In this model, education and parental productivity constituted the main cost drivers in childhood. Lifetime costs of care for individuals with ASD in Germany amounted to about 70% of UK lifetime costs. Here he tells us more about this work.

The challenge of estimating the economic costs of ASD in Germany

Our research is one of the first attempts to shed light on the distribution of costs of autism in Germany, where both prevalence rates and public awareness have recently increased significantly. There is strong demand for autism diagnostic and therapeutic services, putting great pressure on the German health care system. To ensure appropriate resource allocation, especially in times of financial austerity, it is important to have a clear understanding of the key costs associated with autism (e.g. health care, social care, supported employment). Finding this information is challenging, as supporting or caring for people with autism is a multi-agency task, with families also heavily involved. As in the UK, there is no overarching database covering services provided by these many agencies in Germany. Therefore, to establish a first estimate of the costs of autism, data from various organizations were combined in a decision-analytic cost model, and – in some areas – supplemented with cost and prevalence estimates provided by experts.

Our economic model

Our cost model assumes a prevalence rate of ASD in Germany of 1%, and a prevalence rate of intellectual disability in individuals with autism of 50%. At the moment, the model only includes people with ASD *without* an intellectual disability because no data were available to cover the whole spectrum. In other words, the current estimates focus on people with so-called 'high functioning' autism.

The additional costs of autism were calculated for the following areas for different age groups (0-3, 4-6, 7-18, 18+ years) (referring to 2012, and at 2012 prices):

- accommodation
- · health and social care
- education
- productivity loss (for both individuals with autism and their parents) and
- supported employment.

Costs for people with autism but without intellectual disability are driven by educational needs and lack of employment opportunities

Our preliminary results show that for individuals with ASD without intellectual disability, special education for children aged 7-18 years (25% of the total) and parental productivity loss for preschool children (12% of the total) were the main costs during childhood. In adulthood, costs persist, with individual productivity loss the largest cost component (58% of the total). The percentage of autistic adults without employment might be reduced in the future as large companies like SAP have begun to recruit people on the autistic spectrum for specialist jobs. Lifetime costs of caring for a person with autism without intellectual disability are estimated at €766,865, based on an average life expectancy of 70 years for people with autism.

Economic cost of autism in Germany (IQ>70, in € per person/year)



Bachmann, Buescher & Knapp, preliminary data

In comparison to recently compiled UK figures, the distribution of cost components within each age group is similar, but lifetime costs of care in Germany amount to about 70% of the lifetime costs estimated for the UK for someone with autism without intellectual disability. This finding is unexpected, as the German health and social care system is regarded as quite highly priced and resource-intensive. Further research is needed to investigate whether these results are due to fundamental differences in health and social care systems in the UK and Germany, or if other factors, such as greater awareness of ASD and different pathways towards diagnosis and treatment, contribute to these differences.

Next steps

Now that we have an estimate of the current costs of ASD for people without intellectual disability, the next task is to explore how implementing improved approaches to diagnosis and treatment, for example early intensive behavioural interventions, altered diagnostic pathways and improved vocational rehabilitation might influence costs and/or outcomes for individuals with ASD.

Further information

For further information regarding this study, please contact Christian Bachmann (christian.bachmann@med.uni-marburg.de) or Martin Knapp (m.knapp@lse.ac.uk).

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