

Economic Costs of Autism Spectrum Disorder



Executive Summary



April 2007

Synergies Economic Consulting Pty Ltd
www.synergies.com.au

Disclaimer

Synergies Economic Consulting (Synergies) has prepared this advice exclusively for the use of the Autism Early Intervention Outcomes Unit (AEIOU) and for the purposes specified in the report. The report is supplied in good faith and reflects the knowledge, expertise and experience of the consultants involved. Synergies accepts no responsibility whatsoever for any loss suffered by any person taking action or refraining from taking action as a result of reliance on the report, other than AEIOU.

Cover artwork: ©Tim Sharp 2007 'Laser Beak Man - One'. All rights reserved - not to be used without permission. Tim Sharp is 18 years old and has Autism. View his internationally acclaimed artwork at: www.laserbeakman.com

Key findings

This review has produced a preliminary estimate of the annual economic costs of Autism Spectrum Disorder (ASD) in Australia of between \$4.5 billion and \$7 billion. This range reflects the prevalence estimates used in the analysis (ranging between 36.9 and 62.5 per 10,000):

- the costs reflected in these estimates include general and mental healthcare; social services; education; employment; informal care and the impact on well-being (referred to as the 'burden of disease');
- the most significant impacts are the reduction in income arising from reduced employment, as well as the cost of informal care (that is, care provided by family and friends). The impact on well-being is also particularly significant;
- there are a number of costs that have been excluded due to lack of data (such as the costs of underemployment, alternative therapies, the cost of informal care for children and the cost of early intervention strategies). The above estimates are therefore likely to understate the full cost of ASD in Australia.

There is limited information available on the social and economic outcomes for people with ASD in Australia. For example:

- more work is needed on definitively establishing the prevalence of ASD;
- little is known regarding the long-term life outcomes for people with ASD, which will vary considerably across the autism spectrum. These outcomes include education, employment, living independence and social role attainment;
- there is also very limited information on the impact of ASD on families. The costs of informal care have been included but the significant impacts of emotional and financial stress that can arise for families have not been quantified.

Overall, this suggests that a significant group in our community can face a lifetime of disadvantage as a result of the condition. A natural question that arises from this is the response that is required. Whilst this is beyond the scope of the current study, it is evident that there is an ongoing need for community and policy dialogue, in areas such as:

- ensuring accurate and early diagnosis;
- understanding the range of outcomes experienced by children and adults with ASD and the consequent impact of this on the need for services and supports. Even if these supports can't alter the fundamental nature of a person's condition, it could significantly assist them in maximising their capabilities, increase living independence and enhance their quality of life;
- investment in strategies that could potentially alter the outcomes for at least some children with ASD, such as early intervention. In particular, if this improves educational and employment outcomes for even a small number of people, the benefits (via reductions in costs and improvements in quality of life outcomes) will be sizeable.

Executive Summary

Purpose

This study of the economic costs of Autism Spectrum Disorder (ASD) in Australia has been undertaken for the Autism Early Intervention Outcomes Unit (AEIOU).

The objective of this study is to develop a better understanding of the likely resource cost incurred by people with ASD, their carers, Government and society. The cost-based approach that is employed here seeks to estimate the resources required to deliver services that specifically relate to the condition of ASD. In considering the economic cost of ASD, this is defined as:

- expenditure related to the condition, which provides a measure of the resources currently allocated to meet the condition-related needs of individuals with ASD;
- reduced productivity, which arises from diminished workforce participation by individuals with ASD and their carers; and
- reduced quality of life for people with ASD.

In examining the costs of ASD, it may be seen to imply negative connotations about the condition – this is not the intention of this study. In particular, there is no wish to dilute the valued contribution that people with ASD make to the community, which may in some cases be a function of the particular traits of ASD. What this study can do is assist in raising awareness of the costs associated with ASD and the extent of services and supports that many people with ASD (and their families) may require.

Only limited data is available to estimate the costs of ASD in Australia. As a consequence, a number of simplifying assumptions needed to be made and some costs were not captured at all due to lack of data. The estimates here should therefore be considered as providing a preliminary indication of the possible costs of ASD in Australia.

Autism Spectrum Disorder

ASD is a developmental disorder that is characterised by impairments in social activity, communication and imagination. It is spectrum of conditions which includes

autism, Asperger's syndrome (Asperger's), Childhood Disintegrative Disorder, PDD-NOS¹ and Rett's syndrome.

Autism is the more severe condition with impairments likely in all three areas. Further, it is common for people with autism to also have an intellectual disability (studies estimate approximately 75%, although it can be difficult to accurately assess intellectual disability in a child with autism). Those that do not have such a disability will tend to have a higher level of functioning. In this regard, High Functioning Autism (HFA) therefore tends to constitute a further sub-group of ASD.

People with Asperger's syndrome tend to exhibit the features of autism however usually develop language skills at an early age, and do not exhibit any form of intellectual disability. There is some debate regarding the difference between HFA and Asperger's, with some studies showing that the long-term outcomes for people with each condition tend to be similar (with 'outcomes' referring to indicators such as employment, education and living independence).

This study focuses on the two most common forms of ASD, being autism and Asperger's. Given the differences in functioning between the two sub-groups, the outcomes for individuals with each condition, and hence the likely costs, will be different. Estimates are therefore developed for each condition where sufficient data is available to inform a distinction between the outcomes for each group. Further, given the outcomes for individuals with HFA are likely to be more similar to Asperger's rather than autism, HFA and Asperger's have been included in the one category.

Prevalence

Recent studies refer to a significant increase in the prevalence of ASDs over the last ten years. While early studies showed levels as low as four per 10,000, more recent studies suggest a prevalence of as high as 60 to 70 per 10,000. More recent estimates are summarised in the following table.

¹ Pervasive Developmental Disorder that is Not Otherwise Specified.

Prevalence studies: ASD

| Study | Estimate |
|---|---|
| Baird et al (2000) | ASD: 30.8 per 10,000 |
| Chakrabarti & Fombonne (2001) | Autism: 16.8 per 10,000 ASDs other than autism: 45.8 per 10,000 Combined: 62.6 per 10,000 |
| Fombonne (2003) | Conducted a review of 32 recent surveys Overall: 0.7 to 72.6 per 10,000 Most recent (19 studies); 2.5 to 30.8 per 10,000 Concluded estimate: 27.5 per 10,000 for ASD |
| Honda et al (2005) | Autism: 21.1 per 10,000 |
| Shattock & Whiteley (2006) | IQ<70: 20 per 10,000 IQ>70: 71 per 10,000 |
| Centre for Disease Control and Prevention (US – citing data from 2000 and 2002) | ASD: 67 per 10,000 |

One of the possible reasons for the apparent increase in prevalence is improvements in case ascertainment and broader diagnostic criteria, which has also captured more people at the higher functioning end of the spectrum. Another postulated cause is environmental factors, such as increased vaccinations (which has increased the environmental toxins in the population).

The most important study from an Australian perspective was recently undertaken by McDermott et al (2007) for the Australian Advisory Board on Autism Spectrum Disorders.² This review examined a number of possible data sources and considerable inconsistencies were noted. This report concluded that Centrelink data is currently the most comprehensive source of information about the number of people with autism or Asperger's syndrome currently seeking funding. This study estimated a prevalence of:

- 24.2 to 47.2 per 10,000 for autism;
- 12.7 to 15.3 per 10,000 for Asperger's; and
- 36.9 to 62.5 per 10,000 overall.

One of the issues with this data is that it is based on estimates of the prevalence of ASD in children. However, as there is no evidence to suggest that ASD abates in adulthood, these estimates are assumed to be appropriately representative of the prevalence in the entire population.

² McDermott, S., Williams, K., Ridley, G., Glasson, E., & Wray, J. (2007), The Prevalence of Autism in Australia: Can it be Established from Existing Data? Report to the Australian Advisory Board on Autism Spectrum Disorders.

While the authors note residual uncertainties surrounding the actual prevalence of ASD in Australia (at least at the current time), which is due to issues with both diagnosis and information collection, these estimates are consistent with the more recent international evidence and are considered the most appropriate to adopt for the purpose of this study.

Methodology

This study has primarily been based on desktop research. A review of the literature has been undertaken to understand the long-term outcomes for people with ASD, although no comprehensive studies of this have been undertaken in Australia. This review revealed that these outcomes are highly variable, which will also mean that the services and supports required by individuals will vary considerably. As it was not feasible to capture these variations as part of the study, reliance is therefore placed on 'average' outcomes, recognising that there isn't necessarily a 'typical' profile for a person with ASD.

The methodology employed here is similar to the methodologies employed in 'cost of illness' studies. Overall, a conservative approach was taken to the analysis. This meant that where reasonable data could not be sourced to estimate a particular cost, it was not included in the estimates (the costs that were not captured are listed below). The other points to note in relation to the methodology are that:

- it is based on a *prevalence* approach, which estimates the costs incurred by or on behalf of the population of people with ASD in a given year;
- it is an *incremental* analysis, which means that it only captures costs specific to ASD. This recognises that a certain level of cost is likely to be incurred irrespective of whether or not a person has ASD (for example, in healthcare and education) and hence where this is the case, this assumed level of cost is subtracted from the average costs to produce an incremental cost. Areas where there may be cost savings for people with ASD have not been estimated;
- a *bottom-up* approach is generally taken. This estimates the average expenditure per person and applies this to the relevant population.

Transfer effects, such as income support provided by Government and foregone taxation revenue, have not been included here.

Reference is made to sections 3 and 5 of the report for more information regarding the methodology and assumptions underpinning each estimate.

Outcomes

In order to estimate the potential costs of ASD, it is necessary to understand the long-term life trajectory for a person with ASD (recognising that assuming a 'typical' trajectory masks the variability in outcomes that will actually be observed). A review of the literature revealed the following key outcomes for people with ASD.

Outcomes for individuals with ASD – Summary

| Factor | This will mainly impact... | The main cost impacts of this factor are... |
|---|--|--|
| Poor physical and mental health: <ul style="list-style-type: none"> for ASD alone for associated comorbidities | Physical and mental health General well-being | Increased healthcare expenditure Increased social services expenditure |
| Low educational attainment. | Employment Living independence General well-being | Increased education expenditure (special education, education support) Increased social services expenditure |
| Low employment. This can manifest in either: <ol style="list-style-type: none"> unemployment underemployment, which is either: <ul style="list-style-type: none"> only working part-time when want to/can work full time; and/or employed in a job that is not fully utilising the person's skills and capabilities (this is not uncommon for people with Asperger's). | Income (to the individual) Productivity (to the economy) Mental health General well-being | Reduction in productivity Increased social services expenditure (employment support programs, day programs) Reduced quality of life Reduced income for the individual and increased reliance on welfare support (transfer effect) Foregone taxation revenue for government (transfer effect) |
| Reduced living independence | General well-being Mental health | Increased social services expenditure (eg supported accommodation, personal care services) Increased reliance on informal care |
| Reduced social functioning. This can result in social isolation, reduced likelihood of forming long-term relationships etc. | Employment General well-being Mental health | Increased healthcare expenditure Employment impacts Increased reliance on informal care |

There can also be considerable impacts for families:

Outcomes for families with ASD – Summary

| Factor | This will mainly impact... | The main cost impacts of this factor are... |
|--|--|--|
| Employment of primary carer will be affected (more likely to be unable to work, or only maintain part-time work) | Income (to the individual) Productivity General well-being | Reduction in productivity Reduced income for the family and increased reliance on welfare support (transfer effect) Foregone taxation revenue for government (transfer effect) |
| Increased stress | Family relationships (eg can increase likelihood of marital breakdown) | Increased healthcare expenditure |

| Factor | This will mainly impact... | The main cost impacts of this factor are... |
|------------------|--|---|
| | Mental and physical health (eg depression) General well-being | |
| Social isolation | Mental and physical health General well-being | Increased healthcare expenditure |

Reference is made to section 4 of the report for a more detailed review of the outcomes for people with ASD and their families.

The costs that have been examined here include:

- direct costs: healthcare, social services, and education;
- other tangible costs: employment and informal care; and
- intangible impacts: quality of life (typically referred to in these studies as the 'burden of disease').

Cost estimates

As noted above, the methodology used to estimate the costs in each area was largely driven by the availability of data. Reference is made to section 5 of the report of details of the approach used to estimate the costs in each area. This includes:

- a description of the issue;
- the methodology and assumptions employed;
- the cost estimates; and
- the issues and limitations with the estimates. Sensitivity analysis is also conducted where results are seen to be particularly sensitive to key assumptions.

The cost estimates are summarised in the following tables.

Direct costs of ASD per annum

| Category | Total cost (\$'000 Dec 2006) - low prevalence | Total cost (\$'000 Dec 2006) - high prevalence |
|-----------------------|--|---|
| Healthcare | 373,459 | 632,553 |
| Social services | 157,999 | 157,999 |
| Education | 117,155 | 210,632 |
| TOTAL - DIRECT | 648,613 | 1,001,184 |

Other tangible costs of ASD per annum

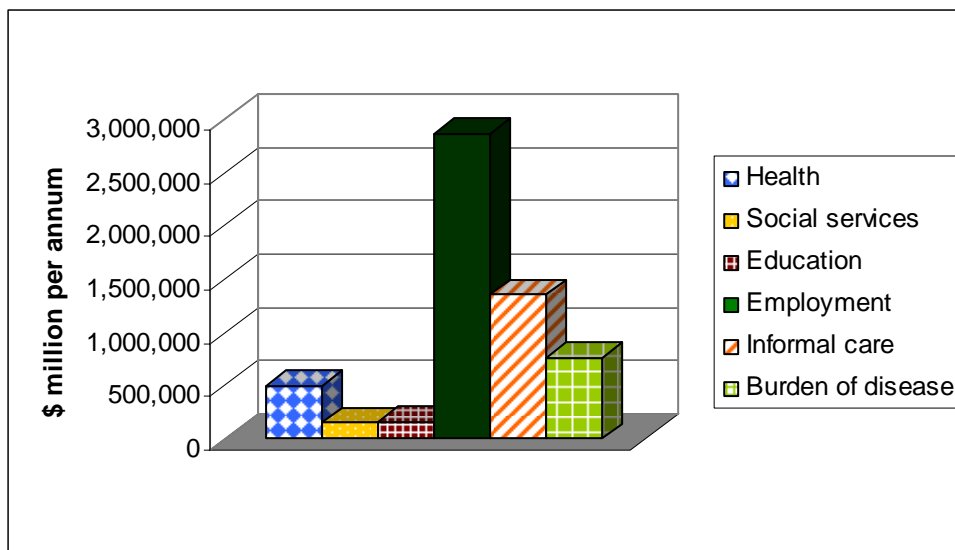
| Category | Total cost (\$'000 Dec 2006) - low prevalence | Total cost (\$'000 Dec 2006) - high prevalence |
|----------------------|--|---|
| Employment | 2,107,038 | 3,635,464 |
| Informal care | 950,963 | 1,776,908 |
| TOTAL - OTHER | 3,058,001 | 5,412,372 |

Intangible costs of ASD per annum

| Category | Total cost (\$'000 Dec 2006) - low prevalence | Total cost (\$'000 Dec 2006) - high prevalence |
|-------------------|--|---|
| Burden of disease | 766,610 | 766,610 |

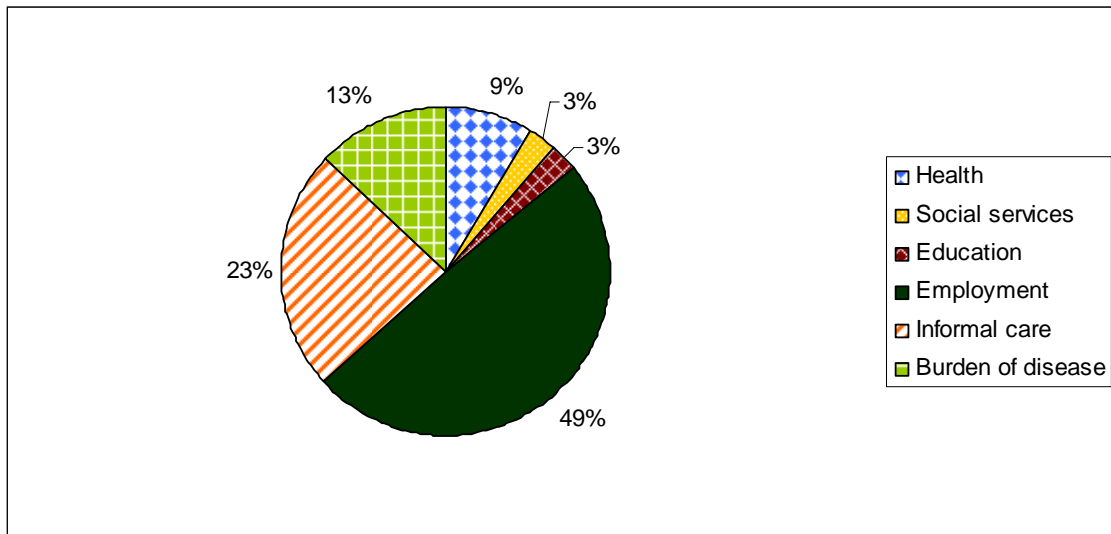
The cost estimates by category are summarised in the following table (taking the mid-point of the range).

Mid-point of cost estimates by category (\$ million)



Overall, this suggests annual total costs of between around \$4.5 and \$7 billion per annum, with a mid-point of \$5.8 billion. This equates to an average *incremental* cost of approximately \$56,000 per person with ASD (this is not the total expenditure – it represents the costs over and above other costs that would normally be incurred by people without ASD). The relative proportion for each cost category is summarised in the figure below.

Relative proportion of each cost category including burden of disease



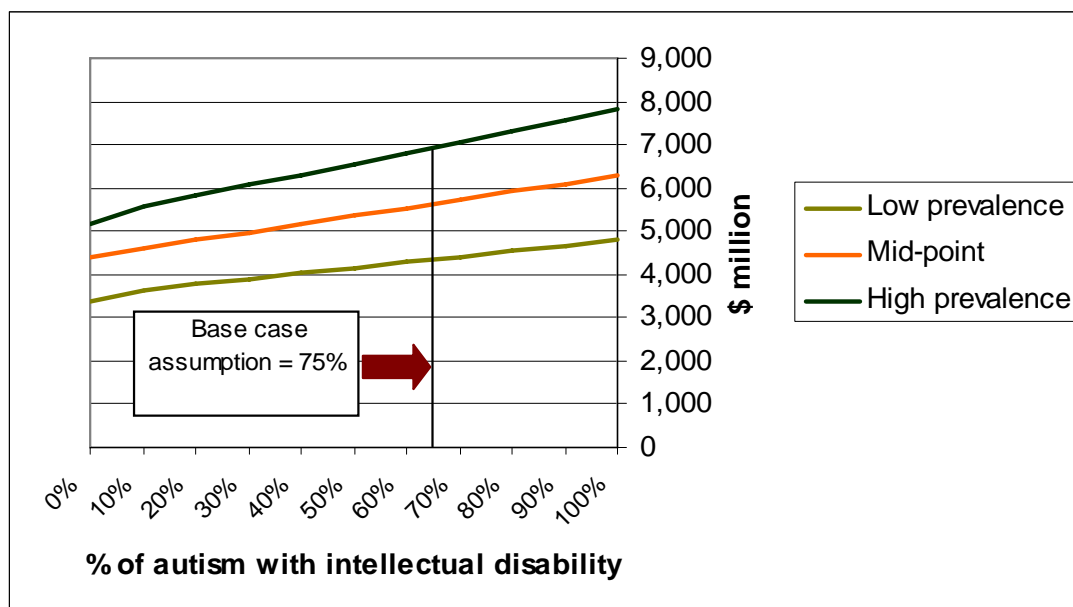
Where possible, estimates have been broken down between autism (excluding HFA) and HFA/Asperger’s. Where data was not available to distinguish between these conditions (eg healthcare), the total costs were simply allocated proportionately between the conditions. The totals for each are summarised below.

Cost estimates by condition

| Condition | Total cost (\$'000 Dec 2006) | Total cost (\$'000 Dec 2006) |
|------------------------|------------------------------|------------------------------|
| | - low prevalence | - high prevalence |
| Autism (excluding HFA) | 2,765,657 | 4,942,771 |
| Asperger’s/HFA | 1,707,567 | 2,237,394 |

The number of people in the category “autism (excluding HFA)” was estimated based on the assumption that 75% of people with autism have an intellectual disability (and will therefore have a lower level of functioning). The overall estimates will be sensitive to this assumption. The following figure plots the total costs across a range of assumptions, taking the mid-point of the range of costs between low prevalence and high prevalence.

Total costs (mid-point between low and high prevalence), varying assumption re proportion of people with autism with a lower level of functioning



As would be expected, the higher the proportion of people with autism that have an intellectual disability (or conversely, the lower the proportion that are higher functioning), the higher the costs.

Costs not included

As highlighted above, one the main difficulties encountered in this study is appropriately reflecting the diverse needs and outcomes for people across the autism spectrum. It is therefore important to recognise that these 'average' estimates mask this underlying variability.

A number of costs have also not been estimated due to lack of data. These include:

- the cost of other conditions on the autism spectrum (eg PDD-NOS);
- early intervention programs;
- comorbid conditions (which is mainly due to a risk of double-counting at least some of these costs);
- the costs of underemployment;
- other costs of unemployment (over and above the productivity impacts);

AEIOU

- alternative therapies;
- additional education support services;
- additional living support services;
- cost of informal care for children with ASD;
- healthcare costs for other family members;
- the costs of family breakdown; and
- household repairs and home modifications.