Economic Costs of Autism Spectrum Disorder in Australia

Updated Study

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Key findings

This review has produced an estimate of the annual economic costs of Autism Spectrum Disorder (ASD) in Australia, updating a previous study completed in April 2007.

This review has produced an updated estimate of the annual economic costs of ASD in Australia, including the burden of disease, of between $8.1 billion (low prevalence) and $11.2 billion (high prevalence), with a mid-point of $9.7 billion (all estimates are in December 2010 dollars).

The total direct and indirect costs (excluding burden of disease) are between $4.2 billion (low prevalence) and $7.3 billion (high prevalence), with a mid-point of $5.8 billion. The estimated cost of reduced quality of life (or the burden of disease) is an additional $3.9 billion. These costs are incremental costs, that is, they only represent the costs incurred for a person with ASD over and above the costs incurred by a person without ASD.

This range reflects prevalence estimates of 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, the cost of informal care (that is, care provided by family and friends) and the burden of disease. The impact on well-being is also particularly significant; and
- 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 continues to be 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; and

- 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 don't alter the fundamental nature of a person's condition, it could significantly assist them in maximising their capabilities by making best use of the person's strengths, increase living independence and enhance their quality of life; and
- investment in strategies that could potentially alter the outcomes for at least some children with ASD, such as best practice 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). This study updates previous estimates prepared by Synergies Economic Consulting in April 2007.

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 directly 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 (the 'burden of disease').

These costs are incremental costs, that is, they only represent the costs incurred for a person with ASD over and above the costs incurred by a person without ASD.

There is a risk that identifying the costs of ASD implies negative connotations about the condition – this is not the intention of this study. Some people with ASD lead highly successful, independent lives. In particular, there is no wish to dilute the valued contribution that people with ASD make to the community, which can often be a function of the particular traits of ASD. Rather, this study seeks to raise 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 a spectrum of conditions which includes autism, Asperger's syndrome (Asperger's), Childhood Disintegrative Disorder, PDD-NOS[1] 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 (some can have a particularly high IQ). 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 & Whitely (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).

To date, the most important study from an Australian perspective was 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
- 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., and Wray, J. (2007). The Prevalence of Autism in Australia: Can it be Established from Existing Data? A Report Prepared for 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.

A more recent study by Parner et al, which compared the prevalence of ASD in children in Western Australia and Denmark, arrived at prevalence rates of 51 per 10,000 in Western Australia.[3] Childhood autism accounted for around 75% of these cases. Preliminary results from two studies at La Trobe University suggest that prevalence could be as high as one in 119 or even one in 100.[4]

We have continued to rely on the estimates produced by McDermott et al because at the current time, this remains the most recent comprehensive published estimates of the prevalence of ASD in Australia.

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, which meant that the probability that the costs are understated is higher than the probability that they are overstated. 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:

[3] Parner, E., Thorsen, P., Dixon, G., de Clerk, N., Leonard, H., Nassar, N., Bourke, J., Bower, C. & Glasson, E. (2011). A Comparison of Autism Prevalence Trends in Denmark and Western Australia. Journal of Autism and Developmental Disorders, February.

[4] Colvin, M. (2009). Autism Rates Much Higher than Previously Thought, http://www.abc.net.au/pm/content/2008/s2634743.htm, 23 July. {Accessed 21 March 2011.}

- 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; and
- 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: • 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: 1. unemployment 2. underemployment, which is either: • 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.	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) Mental and physical health (eg depression) General well-being	Increased healthcare expenditure
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 ($'000 Dec 2010) - low prevalence	Total cost ($'000 Dec 2010) - high prevalence
Healthcare	507,318	859,279
Social services	316,165	316,165
Education	115,964	208,492
TOTAL - DIRECT	**939,447**	**1,383,935**

Other tangible costs of ASD per annum

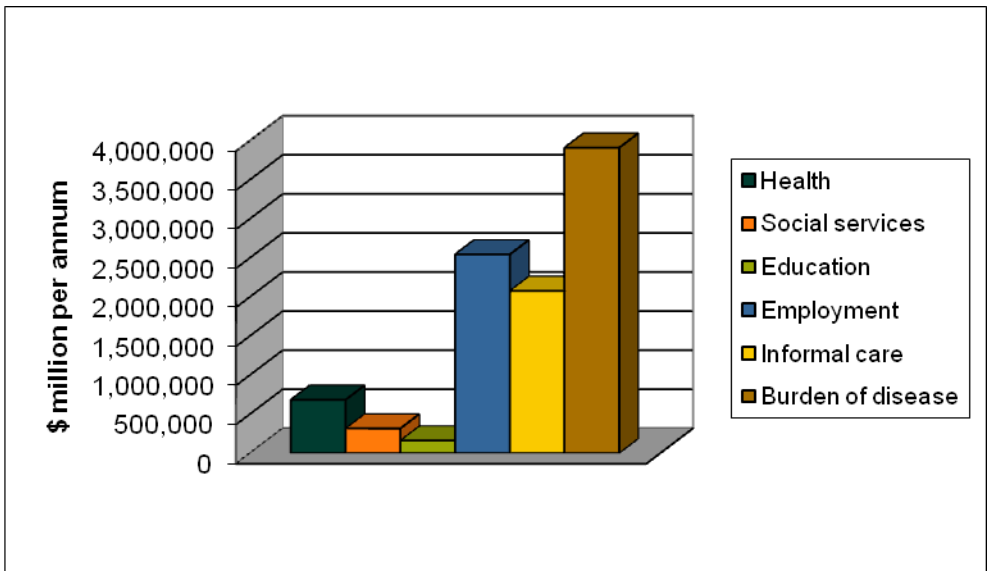
Category	Total cost ($'000 Dec 2010) - low prevalence	Total cost ($'000 Dec 2010) - high prevalence
Employment	1,866,985	3,221,278
Informal care	1,450,050	2,705,683
TOTAL - OTHER	**3,317,035**	**5,926,961**

Intangible costs of ASD per annum

Category	Total cost ($'000 Dec 2010) - low prevalence	Total cost ($'000 Dec 2010) - high prevalence
Burden of disease	3,910,162	3,910,162

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

Mid-point of cost estimates by category ($ million December 2010)

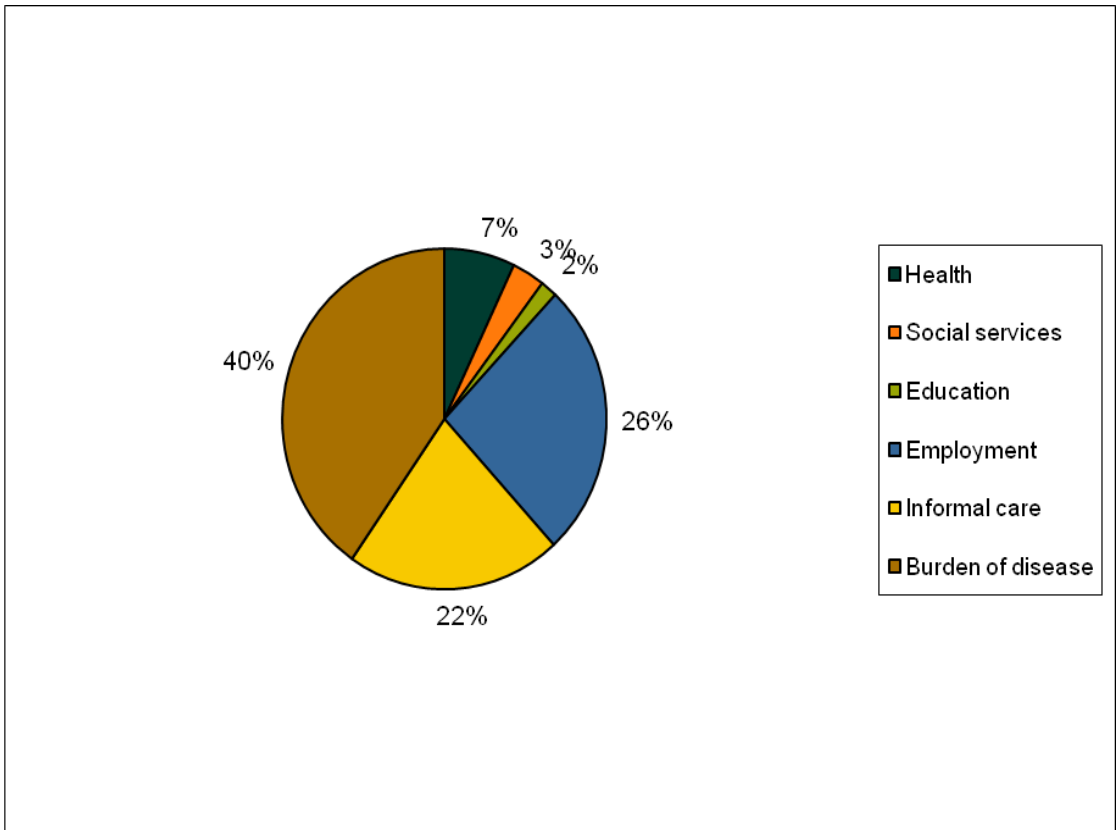


The total direct and indirect costs (excluding burden of disease) are between $4.2 billion (low prevalence) and $7.3 billion (high prevalence), with a mid-point of $5.8

billion. The estimated cost of reduced quality of life (or the burden of disease) is an additional $3.9 billion.

Overall, this suggests annual total costs, including burden of disease, of between around $8.1 billion (low prevalence) and $11.2 billion (high prevalence) per annum, with a mid-point of $9.7 billion. This equates to an average incremental cost of approximately $87,000 per person with ASD (based on the mid-point of our assumed prevalence estimates). These costs are not the total costs – it represents the incremental 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)



This shows that the most significant cost component is the burden of disease. Employment is the next most significant cost category, followed by the costs of informal care. Direct costs, being healthcare, social services and education, comprise around 12% of the total costs.

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 (e.g. healthcare), the total costs were simply allocated proportionately

between the conditions based on prevalence. The totals for each are summarised below.

Cost estimates by condition (including the burden of disease)

Condition	Total cost ($'000 Dec 2010) - low prevalence	Total cost ($'000 Dec 2010) - high prevalence
Autism (excluding HFA)	4,812,633	7,549,639
Asperger's/HFA	3,354,011	3,671,420

The cost estimates in this updated study are materially higher than the outcomes of our previous study ($4.5 billion to $7.2 billion in December 2006 dollars). Apart from the impact of inflation, the main driver of this difference is a materially higher burden of disease estimate. This in turn reflects the higher estimate of Disability Adjusted Life Years, based on the most recent estimates published by the Australian Institute of Health and Welfare, as well as a higher estimate of the Value of a Life Year (which was based on a 2008 report by Access Economics).

Because these increases are largely a function of methodology differences and/or refinements, we would therefore caution against making direct comparisons with our 2006 estimates. We would not interpret these updated results as suggesting that the economic cost of ASD has materially increased. Instead, these updated estimates are likely to better capture the economic costs of ASD at the current time.

We also consider that our results remain conservative. More recent prevalence estimates from studies that have not yet been published are higher than the estimates we have used here. We have also excluded a number of costs where reliable data could not be obtained. This suggests that our estimates of the economic costs of ASD, while significant, could still be understated.

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 (e.g. 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);
- 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.

Contents

Figures and Tables

1 Introduction

1.1 Purpose of this study

The objective of undertaking this study was to develop a better understanding of the likely resource cost incurred by individuals with Autism Spectrum Disorder (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 directly 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 (the burden of disease).

These costs are borne by:

- people with ASD and their families
- Government, on behalf of the individual (for example by the provision of services)
- the wider community (for example via reductions in productivity).

The study shows that there are significant additional costs for people in our community with ASD. The paucity of data and a conservative estimation methodology produce, in all likelihood, an estimate at the lower end of what might be considered the plausible range of estimates.

There is no clear picture on the burden of costs due of data limitations. For example, while there is data available on services provided by Government (although not necessarily specifically in relation to ASD), the extent of the private expenditures incurred by families is largely unknown. The forgone productivity estimates constitute over half of total estimated costs and these costs are borne directly by individuals with ASD and their families. Reduced income earning potential for many implies increased reliance on income support and a reduced standard of living.

There is a risk that identifying the costs of ASD implies negative connotations about the condition – this is not the intention of this study. Some people with ASD lead highly successful, independent lives. 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. Rather, this study seeks to raise awareness of the costs associated with ASD and the extent of services and supports that many people with ASD (and their families) may require.

1.2 Structure of report

This report is structured as follows:

- section 2 provides an overview of ASD, including examining estimates of its prevalence in Australia, which is a key assumption underpinning the costing analysis;
- section 3 provides an overview of the methodology adopted in this study;
- section 4 provides an overview of the possible long-term outcomes for people with ASD and their families. This is used to identify the key costs that are likely to be faced by these groups;
- section 5 details the cost estimates and the specific methodology that has been employed in examining each cost category;
- section 6 provides a brief summary of the cost categories that have not been addressed here; and
- section 7 outlines the main conclusions of the study.

2 Overview of Autism Spectrum Disorders

2.1 Autism Spectrum Disorders

2.1.1 Overview

Autism Spectrum Disorders (ASD) is a category of Pervasive Developmental Disorders (PDD) which includes a number of conditions including:

- autism itself
- Asperger's Syndrome (Asperger's)
- Childhood Disintegrative Disorder (CDD)
- Pervasive Developmental Disorder that is Not Otherwise Specified (PDD-NOS)
- Rett's Syndrome.[5]

ASD is a developmental disorder, primarily characterised by impairments in communication and social activity.[6] Restricted, repetitive and stereotyped patterns of behaviour are a typical feature of the disorder. The World Health Organisation provides the following definition:[7]

> …autism encompasses the following areas of developmental abnormality:
>
> 1) Social relatedness: abnormal social relationships and social developments
>
> 2) Communication: failure to develop normal communication
>
> 3) Imagination: interests and activities that are restricted and repetitive, rather than flexible and imaginative.

The behaviour of the individual in each of these domains will determine which of the five sub-groups the individual is diagnosed under.

Individuals with autism will have impairments in all three areas from an early age, although the extent of the impairments in individuals will vary. More severe cases are often associated with a degree of intellectual disability. The less severe manifestation is

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5 Blaxill, M. (2004). What's Going On? The Question of Time Trends in Autism. Public Health Reports, 119 (6).

6 National Institute of Mental Health (2004). Autism Spectrum Disorders (Pervasive Developmental Disorders), www.nimh.nih.gov/publicat/autism.cfm, p.1.

7 Bassett, K., Green, C., & Kazanjian, A. (2000). Autism and Lovaas Treatment: A Systematic Review of Effectiveness Evidence, British Columbia Office of Health Technology Assessment, The University of British Columbia, p.2.

often referred to as High Functioning Autism (HFA), which is generally considered to be a further sub-group of ASD.

Individuals classified with Asperger's tend to exhibit the features of autism mentioned above however, unlike conventional autism, they develop language skills at the expected age and do not exhibit any form of intellectual disability (some may have a very high IQ). Individuals with CDD also exhibit normal early development before undergoing behavioural, cognitive and language regression between the ages of two and ten.

Rett Disorder is an extremely specific and rare sub-group of ASD. It is a genetic disorder of postnatal brain development that is caused by a single-gene defect and predominantly affects females. The final sub-group is PDD-NOS which applies to individuals who exhibit the features of autism but cannot be appropriately classified into one of the other sub-groups.[8]

This study is predominantly concerned with the 'core' ASDs – autism, HFA and Asperger's – as they are the most common and relevant in terms of analysing the economic costs of ASD to the community. These conditions are examined in more detail below.

2.1.2 Autism

Autism is a neurodevelopmental disorder that impairs the brain's capacity to interpret and organise stimuli in a meaningful way, seriously compromising the individual's development of language and communication skills. The condition is present from birth however it is not usually diagnosed until at least 15-18 months due to the lack of a biological indicator. Along with the language and communication impairments, some studies have estimated that up to 75% of individuals with autism are also born with some degree of intellectual disability[9] (although there are methodological issues with accurately measuring IQ in children with ASD).

All children with autism display a retarded level of spoken language with up to half of individuals with autism never acquiring useful speech. Of those that do acquire useful speech around 75% show abnormal speech features.[10]

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8 Muhle, R., Trentacoste, S. & Rapin, I. (2004). The Genetics of Autism. Pediatrics, 113 (5).

9 Barrett, R (2004). Is There an Autism Epidemic? The Brown University Child and Adolescent Behaviour Letter, p.7.

10 Miranda-Linne, F. & Melin, L. (1997). A Comparison of Speaking and Mute Individuals with Autism and Autistic-like Conditions on the Autism Behaviour Checklist. Journal of Autism and Developmental Disorders, 27 (3).

It is recognised that there is a co-association between autism and learning disability. Autism is common among people with learning disability, and autism in turn impacts all learning (particularly where individuals are more severely affected). O'Brien and Pearson (2004) note that the rate of autism in children with a severe learning disability has been reported to be at least 30%.[11] In turn, it has been estimated that up to 75% of individuals with autism have a severe learning disability. However, the relationships between autism and learning disability are complex and it can be difficult to diagnose autism in people with a profound learning disability.

2.1.3 Higher Functioning Autism and Asperger's Syndrome

The recent improvements to the diagnostic framework for ASD have resulted in the inclusion of a larger portion of individuals without intellectual disability with either normal or above-normal intelligence levels. These individuals can be grouped under two of the sub-groups of ASDs, being HFA or Asperger's.

The original description of Asperger's emphasised social disability, difficulties in reading non-verbal cues, focusing on unusual factual topics, alienation from peers and a lack of understanding of social and conversational rules.[12] Although this definition makes Asperger's easily distinguishable from typical autism (that is, individuals with Asperger's have no severe language impairments), this distinction is not necessarily as clear with the large portion of individuals with autism who do not suffer any intellectual disability, causing problems for accurate diagnosis (that is, those with HFA).[13]

In the past there has been very limited evidence available for experts to use in an attempt to distinguish between HFA and Asperger's. Instead of attempting to differentiate between the two, many experts have simply used them interchangeably and grouped them under the one diagnostic category.[14]

These problems with differentiating between the two disorders have led to the formation of a new proposal for a diagnostic framework that focuses more on the unique characteristics of Asperger's. This approach emphasises making distinctions between children who isolate themselves (typical of autism) and those who seek attention but in a socially insensitive manner (behaviour exhibited by children with

[11] O'Brien, G. & Pearson, J. (2004). Autism and Learning Disability. Autism, Vol.8, No.2, p.127.

[12] Klin, A., Pauls, D., Shultz, R. & Volkmar, F. (2005). Three Diagnostic Approaches to Asperger Syndrome: Implications for Research. Journal of Autism and Developmental Disorders, 35 (2).

[13] Klin, A., Pauls, D., Shultz, R. & Volkmar, F. (2005).

[14] Klin, A., Pauls, D., Shultz, R. & Volkmar, F. (2005).

Asperger's).[15] Another point of difference that is emphasised by this approach can be found in the linguistic properties of the two disorders. Children with HFA experience some problems with language delay and stereotyping whilst children with Asperger's experience problems with the communicative use of language, but not necessarily with language itself.[16]

The main feature that differentiates Asperger's from autism is that children with Asperger's do not experience the delay in speech development that is evident in children with typical autism. This means that the diagnosis age for children with Asperger's is later than it is for autism, as experts must wait for behavioural symptoms to become evident before a diagnosis can be made.[17]

One of the key issues for this study is the extent to which there is likely to be a difference in the long-term outcomes between an individual with HFA and an individual with Asperger's. The outcomes studies that have been reviewed do not yield any notable differences. That is, while there are some fundamental differences that are particularly evident in childhood, the long-term outcomes into adulthood are not materially different. This will be examined in more detail in section 4.

2.2 Diagnosis

While a number of children are diagnosed with ASD at a relatively early age, diagnosis may not occur until late teens or even adulthood. The National Institute of Mental Health (2004) estimates that only 50% are diagnosed before kindergarten.[18] Given strategies such as early intervention can improve the long-term outcomes for some children with ASD, if diagnosed sufficiently early, late diagnosis is a significant issue.

A study by Barnard et al (2001) of adults with ASD noted that only 43% of lower functioning adults were diagnosed before the age of five, notwithstanding that they had urgent needs.[19] 18% of lower functioning adults were not diagnosed until the age of sixteen or older. This increases where the individuals are functioning at a higher level. In this study, 26% of individuals with higher functioning autism were not

[15] Klin, A., Pauls, D., Shultz, R. & Volkmar, F. (2005).

[16] Klin, A., Pauls, D., Shultz, R. & Volkmar, F. (2005). Other symptoms such as one-sided verbosity, strength in verbally mediated skills and the presence of factual interests that interfere with general learning and social relationships are other characteristics that can be used to identify a child with Asperger's as opposed to an individual with HFA.

[17] McConachie, H., Le Couteur, A. & Honey E. (2005). Can a Diagnosis of Asperger Syndrome be made in Very Young Children with Suspected Autism Spectrum Disorder? Journal of Autism and Developmental Disorders, 35 (2).

[18] National Institute of Mental Health (2004). p.2.

[19] Barnard, J., Harvey, V., Potter, D., & Prior, A. (2001). Ignored or Ineligible? The Reality for Adults with Autism Spectrum Disorders, The National Autistic Society, London, p.13.

diagnosed until age sixteen or over, with this increasing to 46% of individuals with Asperger's.[20] This can also mean that higher functioning individuals often do not receive the assistance they may need, as their needs are more difficult to classify.[21]

A recently published study on the prevalence of ASD in Australia identified a number of issues with respect to diagnosis, mainly in terms of potential inconsistencies in the application of diagnostic processes:[22]

> Diagnosis and assessment services vary between and within States and Territories in regard to the personnel involved in the diagnosis and assessment process and the diagnostic classification systems and tools used. Although there was consistency in the use of DSM-IV between services reporting the classification system they used, not all services reported this information and no information was available from the private sector.

This will have implications for prevalence estimates. More importantly, it could also have implications for access to services and funding.

2.3 Prevalence

An important assumption underpinning the cost estimates is the prevalence of ASD in Australia. This is examined in more detail below.

2.3.1 Recent increase in prevalence of ASDs

Recent studies in both the UK and the US have shown a ten-fold increase in the prevalence of ASDs over the last ten years. Current statistics place the incidence level of ASDs at between 30 and 60 cases per 10,000. Although lacking in precision these figures are alarming when compared to an equivalent study from 1966 which estimated incidence levels at approximately 4 per 10,000.[23]

The uncertainties surrounding the diagnostic boundaries of ASDs make a precise estimation of prevalence levels extremely difficult. In their UK study Chakrabarti and Fombonne (2001) estimated the prevalence of autism alone to be 16.8 per 10,000 with a 95% confidence interval of 11.0 to 24.6. They also estimated the prevalence of ASDs other than autism to be at 45.8, giving a combined incidence rating for all disorders

[20] Barnard, J., Harvey, V., Potter, D., & Prior, A. (2001).

[21] Loynes, F. (2001). The Impact of Autism, A Report Prepared for the All Party Parliamentary Group on Autism, p.8.

[22] McDermott, S., Williams, K., Ridley, G., Glasson, E., & Wray, J. (2007).

[23] Rutter, M. (2005). Incidence of Autism Spectrum Disorders: Changes over time and their meaning. Acta Paediatrica, 94 (1).

within the autistic spectrum of 62.6 per 10,000, which is significantly higher than has been previously estimated.[24] Another study by Baird et al (2000) estimated the prevalence of ASDs at 30.8 per 10,000.

A further study that produced interesting results was a review by Honda et al (2005) that was conducted in Yokohama, Japan. This report concentrated specifically on the prevalence of autism in the population and excluded the other conditions in the spectrum. The study produced a prevalence rating of 21.1 per 10,000.[25]

In 2003 Fombonne conducted an updated review of surveys that had been conducted on the prevalence of ASD.[26] Throughout all 32 surveys 2,380 subjects with ASD were identified. Overall, prevalence estimates ranges from 0.7 to 72.6 per 10,000. For the nineteen most recent surveys the estimates ranged from 2.5 to 30.8 per 10,000, with an average of 11.1. He concludes that:[27]

> Taking 10/10,000 as the base rate for autism, a rate of 27.5/10,000 for the combination of all PDDs can be derived. It could be well that, because these surveys were not focusing primarily on the non autistic group, the actual rate of combined pervasive developmental disorders could be even higher, in the neighbourhood of 60 to 70/10,000 as suggested by 3 recent surveys.

Shattock and Whiteley (2006) cite data from the National Autistic Society in the UK, which suggests a prevalence of 20 per 10,000 for people with ASD with an IQ of less than 70 and 71 per 10,000 for people with an IQ of more than 70.[28]

The Centre for Disease Control and Prevention (2007) released results of a survey across 14 US states, which estimates prevalence for ASD of approximately 66 per 10,000.[29]

The incidence level for Asperger's has been estimated at between 14% and 19% of all individuals with ASD whilst the rates for CDD and Rett's Syndrome are extremely low.[30]

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24 Rutter, M. (2005).

25 Rutter, M. (2005).

26 Fombonne, E. (2003). Epidemiological Surveys of Autism and Other Pervasive Developmental Disorders: An Update. Journal of Autism and Developmental Disorders, Vol.13, No.4.

27 Fombonne, E. (2003).

28 Shattock, P. & Whitely, P. (2006). The Changing Prevalence of Autism, Autism Research Unit, University of Sunderland, http://osiris.sunderland.ac.uk/autism/incidence.htm.

29 Center for Disease Control and Prevention (2007). "Frequently Asked Questions – Prevalence", http://www.cdc.gov/ncbddd/autism/faq_prevalence.htm#whatisprevalence.

30 Blaxill, M. (2004).

2.3.2 Reasons for the Increase in Prevalence

As noted above studies have shown significant increases in the prevalence of ASD in the population. There are two general lines of argument in explaining this recorded increase. The first explanation is that the last few decades have seen a genuine increase in the prevalence of ASDs in the population, perhaps as a result of increased vaccinations, which has increased the presence of environmental toxins in the population. The other argument is that improvements in the diagnostic criteria and case ascertainment have simply allowed experts to detect more cases of individuals with an ASD, thus resulting in the increased prevalence rates.[31]

The consensus view in the literature is that the increase in prevalence in recent decades can be predominantly attributed to improvements in case ascertainment and broader diagnostic criteria.[32] This has resulted in a greater number of individuals with HFA and Asperger's being identified who were not diagnosed with the disorder in past decades due to their milder symptoms.[33] This argument is supported by the significant increase in the portion of individuals that have been diagnosed with an ASD with intelligence levels in the normal range.[34]

2.3.3 Australian Studies

The first major study into the prevalence of ASD in Australia was conducted in New South Wales and Western Australia in 1999/2000. In WA, 252 children between the ages of 0 and 14 were identified with an ASD. 169 of these children had autism whilst 83 suffered from other disorders in the spectrum such as Asperger's, Rett's Syndrome, CDD or PDD-NOS. The incidence of autism for the 0-4 age group was 5.5 per 10,000 and 8 per 10,000 for all ASDs.[35]

In NSW, 532 children were identified with an ASD, 400 of which were diagnosed with autism with the other 132 suffering from other disorders in the spectrum (Asperger's, Rett's Syndrome, PDD-NOS and CDD). The incidence of ASD for the 0-4 age group in NSW was 4.3 per 10,000 and 5.1 per 10,000 for all ASDs. These figures were comparable with an earlier study conducted in the Barwon region of Victoria, which produced an

[31] Kurita, H. (2006). Disorders of the Autism Spectrum. Lancet, 368.

[32] Kurita, H. (2006).

[33] Kurita, H. (2006).

[34] Rutter, M. (2005).

[35] Williams, K. et al. (2005). Incidence of Autism Spectrum Disorders in Children in Two Australian States. The Medical Journal of Australia, 182 (3).

incidence level of 4.26 children per 10,000.[36] These estimates are low compared to some of the estimates that have been made in other jurisdictions.

A comprehensive review of the prevalence of ASD in Australia was recently undertaken by McDermott et al for the Australian Advisory Board on Autism Spectrum Disorders.[37] This review examined a number of possible data sources including State and Territory agencies, Autism Associations, data collected under the Commonwealth State/Territory Disability Agreement (CSTDA) and Centrelink.

Given there were considerable inconsistencies between the different data sources examined, this report concluded that the prevalence of ASD in Australia is currently uncertain. They note that:[38]

> The collected data, through their inconsistency, confirm that there are significant differences in the way children with ASDs are diagnosed, directed to services, and are offered different support schemes across Australia.

They conclude that the Centrelink data is the most comprehensive source of information about the number of people with autism or Asperger's syndrome currently seeking funding:[39]

> It provides information about the minimum number of individuals living with these diagnoses each year. However, these data are best for younger children diagnosed with either Autism or Asperger Disorder. Centrelink data are incomplete in relation to individuals between 13-16 with Autism and Asperger Disorder and provides no information about individual(s) with PDD-NOS who may also require services to maximise their potential abilities and to minimize the burden of care for themselves, their families and the community.

The estimates based on the Centrelink data are provided in the following table.

[36] Williams, K. et al. (2005).

[37] McDermott, S., Williams, K., Ridley, G., Glasson, E., & Wray, J. (2007).

[38] McDermott, S., Williams, K., Ridley, G., Glasson, E., & Wray, J. (2007). p.60.

[39] McDermott, S., Williams, K., Ridley, G., Glasson, E., & Wray, J. (2007). p.60.

Table 1 Estimated national prevalence based on Centrelink data

	2003			2004			2005		
	0-5	6-12	13-16	0-5	6-12	13-16	0-5	6-12	13-16
Autism									
Prevalence / 10,000	15.3	35.7	17.4	17.7	41.3	20.3	20.3	47.2	24.2
95% C.I.[a]	14.7–15.9	34.8-36.5	16.6-18.2	17.0-18.4	40.4-42.3	19.5-21.2	19.6-21.1	46.2-48.1	23.2-25.1
Asperger's Syndrome									
Prevalence / 10,000	0.9	10.2	8.4	1.3	11.9	10.2	1.7	15.3	12.7
95% C.I.[a]	0.7-1.0	9.7-10.6	7.9-9.0	1.1-1.5	11.4-12.4	9.6-10.7	1.5-1.9	14.8-15.9	12.0-13.4

a Confidence interval

Source: 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, p.31.

This data shows a significant increase in the prevalence of ASD between 2003 and 2005. Focussing on the 6-12 and 13-16 year age categories (which is considered appropriate given not all children would have been diagnosed by age 5), the most recent 2005 data suggests a prevalence of between 24.2 and 47.2 per 10,000 for autism and between 12.7 and 15.3 per 10,000 for Asperger's, resulting in a combined prevalence for autism and Asperger's of between 36.9 and 62.5 per 10,000.

The reasons for the differences between age categories is not clear, particularly the decrease in prevalence in the 13 to 16 years age group. The possible reasons identified include:[40]

- it reflects the increase in the actual prevalence through time, with the lower prevalence in older age groups reflecting previous prevalence estimates;
- improvements in functioning by some children;
- the death of children with ASD; and/or
- changes in service usage, poorer identification of children as they leave school and child health services or decreased requirements for ASD-specific services. This could also be due to changes in the funding needs of families as the children age, or changes to the way older individuals access funding.

Overall, the estimates are seen to be consistent with a number of recent studies undertaken in other jurisdictions. The report makes a number of recommendations for improving future data collection and highlights the importance of diagnostic

[40] McDermott, S., Williams, K., Ridley, G., Glasson, E., & Wray, J. (2007).

validation to assess the reliability of a particular data source in estimating the 'true' prevalence of ASD.

A recent study by Parner et al, which compared the prevalence of ASD in children in Western Australia and Denmark, arrived at prevalence rates of 51 per 10,000 in Western Australia.[41] Childhood autism accounted for around 75% of these cases. Preliminary results from two studies at La Trobe University suggest that prevalence could be as high as one in 119 or even one in 100.[42]

Despite the high degree of variance in the different studies on the prevalence of autism and the other disorders within the spectrum, including the data issues identified by McDermott et al, it seems reasonable to adopt this range given it remains the most recent comprehensive published estimates of the prevalence of ASD in Australia. Their estimates are also reasonably consistent with overseas studies. The remaining people with ASD are diagnosed with PDD-NOS, with a very small percentage suffering from the rare Rett Syndrome or CDD.

2.3.4 A childhood disorder?

ASD is often categorised as a 'childhood disorder'. Seltzer et al note that some symptoms of ASD abate later in life, although the core symptoms, such as social deficits and ritualising and repetitive behaviours, generally remain.[43] Where improvements are seen, they generally take the form of the acquisition of a new skill and a decline in maladaptive behaviours:[44]

> Nevertheless, studies have shown that, few, if any, individuals who receive a diagnosis of autism in childhood recover fully and achieve levels of functioning typical of their age peers.

However, some do outgrow the diagnosis, particularly those with the least severe symptoms. There may also be periods where symptoms become aggravated and for some, may even worsen. In particular, improvements in restricted and repetitive

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41 Parner, E., Thorsen, P., Dixon, G., de Clerk, N., Leonard, H., Nassar, N., Bourke, J., Bower, C. & Glasson, E. (2011). A Comparison of Autism Prevalence Trends in Denmark and Western Australia. Journal of Autism and Developmental Disorders, February.

42 Colvin, M. (2009). Autism Rates Much Higher than Previously Thought, http://www.abc.net.au/pm/content/2008/s2634743.htm, 23 July. {Accessed 21 March 2011.}

43 Seltzer, M., Shattuck, P., Abbeduto, L., & Greenberg, J. (2004).Trajectory of Development in Adolescents and Adults with Autism. Mental Retardation and Developmental Disabilities Research Reviews, vol.10, p.236.

44 Seltzer, M., Shattuck, P., Abbeduto, L., & Greenberg, J. (2004). p.239.

behaviours are less likely, with the complexity of these behaviours potentially increasing into adulthood. Seltzer et al state:[45]

> It appears that modest improvements in symptoms is evident, at least in some individuals, from childhood to adolescence and into adulthood. However, this improvement seldom leads to levels of functioning in the normal range, which reinforces the notion that autism is generally a lifelong condition. Moreover, improvement is not seen for all behaviours and not all individuals improve. Some individuals decline, especially if they are very low functioning, have very severe symptoms, or develop seizures.

Hence, there is therefore no evidence to indicate that the symptoms of ASD substantially subside in adulthood. The estimates produced by McDermott et al were based on children. However, in the absence of any information on the prevalence of ASD in the adult population in Australia, or definitive evidence that the symptoms do in fact subside in adulthood, the prevalence estimates for children are applied to the adult population. Further research on this is needed, including specific estimates on the prevalence of ASD in adults for Australia.

2.4 Comorbidities

ASD is often associated with a number of other conditions. However, the prevalence of these other conditions in people with ASD can be very difficult to establish, given it can be difficult to separate the symptoms of ASD from the symptoms of the comorbid condition. This is particularly the case with psychiatric conditions, including depression. According to Ghaziuddin, even less is known about the comorbidities in individuals with Asperger's compared to autism.[46]

2.4.1 Intellectual disability

As noted above, it is common for individuals with autism to have a degree of intellectual disability. A diagnosis of intellectual disability is made based on three criteria: an IQ score of less than 70, adaptive skills deficits and an age of onset prior to 18 years. Although children with autism will automatically meet the final two criteria, intelligence itself is totally independent of the condition.[47]

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45 Seltzer, M., Shattuck, P., Abbeduto, L., & Greenberg, J. (2004). p.245.

46 Ghaziuddin, M. (2002). Asperger Syndrome: Associated Psychiatric and Medical Conditions. Focus on Autism and Other Developmental Disabilities, 17(3).

47 Edelson, M. (2006). Are the Majority of Children with Autism Mentally Retarded? A Systematic Evaluation of the Data, Focus in Autism and other Developmental Disabilities. 21 (2).

Results across surveys have varied greatly with some studies claiming the level of intellectual disability among individuals with an ASD are as low as 40% and others reporting a prevalence rate of closer to 75%.[48] It is most likely that the rate for intellectual disability in autism is in the higher region of this range as these individuals are likely to exhibit higher rates than those with milder PDDs.

A study conducted by Barton and Volkmar concluded that where individuals with ASD have intellectual disability there will be an increased likelihood of other medical conditions. An incidence rating for medical conditions of 20% was reported among the individuals of an IQ with less than 50 whilst only 7% was recorded for those with an IQ of above 50.[49] This study demonstrates that the prevalence of medical conditions in individuals with ASD increases as IQ decreases, thus demonstrating a fundamental link between intellectual disability and co-morbid medical conditions.

2.4.2 Mental health problems

The accurate and reliable diagnosis of a psychiatric condition in children with ASD is vital in terms of measuring the burden that the condition places on both the individual and the family. However, the significant theory of mind and communication deficiency problems that are associated with ASD make such a diagnosis difficult. It becomes difficult to determine whether the problems being experienced are simply a by-product of the individual's ASD or indeed a separate psychiatric disorder.[50]

Several studies have been conducted investigating the link between ASD and psychiatric conditions with most reporting a strong association. However, it must be taken into account that the specific results varied greatly as a result of the differences in sample methods, criteria and methodology.[51] A study by Leyfer et al found that the most common psychiatric condition diagnosed in children with ASD was a specific phobia, with a fear of loud noises being the most common at 10%.[52] Obsessive Compulsive Disorder (OCD) was the second most prominent psychiatric condition at 37%. 10% of individuals with ASD also met the DSM-IV criteria for major depression, with an additional 14% falling just short of these criteria.

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48 Edelson, M. (2006).

49 Barton, M. & Volkmar, F. (1998). How Commonly are Known Medical Conditions Associated with Autism? Journal of Autism and Developmental Disorders, 28 (4).

50 Leyfer, O., et al. (2006). Comorbid Psychiatric Disorders in Children with Autism: Interview Development and Rates of Disorders. Journal of Autism and Developmental Disorders, 36.

51 Leyfer, O., et al. (2006).

52 Leyfer, O., et al. (2006).

Another study of interest in relation to the link between ASD and psychiatric conditions was conducted by Tantam, Wing, Ghaziuddin and Kurita, involving the analysis of 85 individuals with Asperger's.[53] Of the sample it was determined that 35% met the criteria for a psychiatric condition other than a developmental disorder. Most of these patients were diagnosed with various forms of psychosis whilst depression and OCD also featured prominently.

These results were supported by Howlin in her literature review on co-morbid psychiatric conditions among individuals with PDD-NOS. Howlin concluded that the most common co-morbid conditions for people with PDD-NOS were depression and severe anxiety followed by bipolar and manic disturbances. The review also demonstrated strong links between PDD and schizophrenia, delusional disorder, suicidal behaviour, paranoia, sleep disturbance and a number of other psychiatric conditions.[54]

2.4.3 Major Depressive Disorder

Evidence suggests that the prevalence of major depressive disorder in ASD is higher than the rate observed in the general population. A number of studies have examined this, with prevalence estimates for depression in ASD ranging from 10% to over 20%.[55] This compares to estimates for the general population ranging from between 4.5% and 10%, although on average are likely to be at the upper end of this range.

2.4.4 Obsessive-Compulsive Disorder

In relation to OCD, research suggests that there is a significantly higher prevalence of the condition in individuals with ASD than is observed in the general population. For example, Leyfer et al (2006) cites OCD as the second frequent disorder in ASD, with a prevalence rating of 37%.[56] Various epidemiological surveys in the US during the early 1990s estimated a prevalence rating for the condition of approximately 2.1% in the general population.[57] However, other studies have estimated even lower prevalence rates of below 1%.

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53 Sverd, J. (2003). Psychiatric Disorders in Individuals with Pervasive Developmental Disorder. Journal of Psychiatric Practice, 9 (2).

54 Sverd, J. (2003).

55 For example, refer: Leyfer (2006), Howlin et al (2003), Barnard et al (2001) & Tantum (1991).

56 Leyfer, O., et al. (2006). p.853.

57 DuPont, R. (1995). Economic Costs of Obsessive-compulsive Disorder. Medical Interface, 8 (4).

2.4.5 Epilepsy

In recent times there has been a great deal of attention drawn to the link between ASD and epilepsy with a number of studies being conducted on the issue. These studies exhibit a wide range of estimations in relation to the frequency of epilepsy in individuals with ASD.[58]

Whilst some studies have reported a prevalence rate of as low as 5%, other studies, such as that conducted by Danielsson et al, have reported rates of closer to 40%.[59] Despite these large variations in estimates it is generally accepted by all experts that epilepsy is more common among individuals with ASD than it is in the general population with most estimating a prevalence rate of between 10% and 30% in ASD,[60] compared to around 3% in the general population.

2.4.6 Tuberous Sclerosis Complex (TSC)

TSC is an autosomal dominant disorder characterised by hamartomas and hamartias in multiple organs including the brain, heart and kidney. The condition is associated with seizure disorder and intellectual disability.[61] One prevalence study on TSC in the general population estimated that the condition affects only 1 in 6,000 live births.[62] Studies have shown that for all individuals with TSC between 60 and 80% are affected by epilepsy and 50 to 60% are categorised as having an intellectual disability.[63]

Reports and studies that have been conducted in recent times have demonstrated a higher co-occurrence between ASD and TSC than could be expected by chance. Hunt and Dennis conducted the first major study in this area in 1987 by examining 90 individuals with TSC, reporting that 45 demonstrated symptoms of ASD by the age of five. A follow-up study was conducted by Hunt and Shepherd in 1993 under a more refined diagnostic framework which reported a prevalence rate of 24%.[64]

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58 Parkinson, G. (2006). Pragmatic Difficulties in Children with Autism Associated with Childhood Epilepsy. Paediatric Rehabilitation, 9 (3).

59 Danielsson, S., et al. (2005). Epilepsy in Young Adults with Autism: A Prospective Population-based Follow-up Study of 120 Individuals Diagnosed in Childhood. Epilepsia, 46 (6).

60 Gabis, L., Pomeroy, J. & Andriola, M. (2005). Autism and Epilepsy: Cause, Consequence, Comorbity or Coincidence? Epilepsy & Behavior, 17 (4).

61 Baker, P., Piven, J. & Sato, Y. (1998). Autism and Tuberous Sclerosis Complex: Prevalence and Clinical Features. Journal of Autism and Developmental Disorders, 28 (4).

62 Rendtorff, N., et al (2005). Analysis of 65 Tuberous Sclerosis Complex (TSC) Patients by TSC2 DGGE, TSC1/TSC2 MLPA, and TSC1 Long-Range PCR Sequencing, and Report of 28 Novel Mutations. Human Mutation, 26 (4).

63 Bolton P. & Griffiths, P. (1997). Association of Tuberous Sclerosis of Temporal Lobes with Autism and Atypical Autism. Lancet, 349 (9049).

64 Baker, P., Piven, J. & Sato, Y. (1998).

The proposed link between TSC and ASD is further supported by epidemiological investigations which demonstrate that the risk of ASD is between 200 and 1000 times greater in individuals with TSC than the general population. In addition to this, the risk of TSC is 100 to 300 times greater for individuals with ASD than the general population.[65]

Although these results must be interpreted with caution due to the limitations that exist in this field of research, even allowing for a large margin for error there is evidence of a clear link between ASD and TSC.

[65] Bolton P. & Griffiths, P. (1997).

3 Methodology

3.1 Understanding and identifying costs

This review is largely based on desktop research to identify and assess the main costs of ASD. One approach that could have been undertaken would be to collect data from people with ASD and their families, however, to produce reliable estimates this data would have had to be collected over an extended time period, involving a sample of a size and constitution that would be considered appropriately representative of the population of people with ASD.[66] A summary of some of the alternative approaches to examining costs is provided in Appendix 7A.

The first task in the analysis was to develop an understanding of ASD and the impact it has on the long-term outcomes for an individual. A review of the literature was undertaken, focussing on the key studies that have examined long-term outcomes for children and adults with ASD (the results of this review are summarised in section 4). What was evident from this review is that these outcomes are highly variable. This to some extent could be due to the different approaches taken by each study, as well as differences in the sample groups of people with ASD.

More fundamentally, however, it reflects the spectrum nature of the disorder and the varying needs of individuals for services and supports. While there are different diagnostic classifications along the spectrum, very different outcomes could be observed for a group of individuals with the same diagnosis. However, it is not feasible to capture these differences as part of the study. Hence, reliance tends to be placed on 'average' outcomes, recognising that there isn't necessarily a 'typical' profile for a person with ASD.

3.2 Measuring costs

3.2.1 Incidence or prevalence approach

Costs of illness studies employ either an incidence or prevalence approach. An incidence approach identifies a cohort of people with the condition over a specified time period (typically a year) and then estimates the direct and indirect lifetime costs for this group (which can then be converted to an annual equivalent cost). A prevalence approach identifies a cohort of people with the condition and then

[66] In this regard, reference is made to the research methodology developed by Jarbrink, Knapp and Fombonne, which provides a more structured framework for collecting data from people with ASD and their families. Refer: Jarbrink, K., Fombonne, E., & Knapp, M. (2003). Measuring the Parental, Service and Cost Impacts of Children with Autistic Spectrum Disorder: A Pilot Study. Journal of Autism and Developmental Disorders, 33(4).

estimates the costs for that group for a given year. Using certain assumptions, these estimates could be extrapolated to produce lifetime costs.

One key advantage of the incidence approach is that it seeks to capture changes in service utilisation throughout an individual's lifetime, which could be a function of changes in the need for services or be driven by other factors such as changes in family circumstances (for example, the ageing or death of a carer). Practically, however, it is extremely difficult to identify and predict such changes with any certainty. The prevalence approach therefore tends to be most commonly applied in practice (for example, this approach was used in the recent study by Ganz).

Ganz summarises the differences between the two approaches as follows:[67]

> Because of this richness and sensitivity to the evolution of an illness or disorder, the cost estimates derived from the incidence-based approach closely estimates the value of prevention…Costs derived under the prevalence-based approach represent the costs to care for people with autism at a point in time rather than the lifetime profile of autism itself and, therefore, the prevalence-based cost estimates more closely represent the cost of treatment and caring for those with autism…Cost estimates based on the prevalence-based approach are useful for understanding current expenditure patterns and for the allocation of current resources, whereas cost estimates based on the incidence-based approach are more appropriate for understanding dynamic patterns and for making decisions about resource allocation that involve future time periods, as when making decisions about future treatment or research patterns.

Given the data limitations, this review is based on a prevalence approach.

3.2.2 Direct and other costs

Costs can be categorised in a number of ways. A common approach in cost of illness studies is to distinguish between 'direct' and 'indirect' costs. Direct costs include those costs that are directly incurred by or on behalf of the individual, such as medical and education expenditures. These costs could be incurred by the individual, their family, Government (on behalf of the individual) or some combination thereof.

Studies often classify costs such as productivity losses (for both the individual and carers) as 'indirect costs'. For example, Kleinman et al defines these costs as follows:[68]

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[67] Ganz, M. (2006). The Costs of Autism, in Moldin, S. & Rubenstein, J. (eds.). Understanding Autism: From Basic Neuroscience to Treatment, CRC Press.

[68] Kleinman. L. et al (2003). Costs of Bipolar Disorder. Pharmacoeconomics, 21(9), p.608.

> Indirect costs are associated with the level of health impairment and how this impairment interferes with work-related and other productivity.

'Indirect costs' has its origins in accounting and tends to refer to those costs that cannot be directly attributed to the individual. However, costs such as the income losses from unemployment and informal care provision can be attributed directly to the individual and hence the term 'indirect' is not necessarily an appropriate classification.

In their cost of illness studies, Access Economics tend to classify the different cost categories under the following headings:[69]

- direct financial costs (e.g. healthcare)
- other financial costs (e.g. productivity)
- other non-financial costs (e.g. quality of life impacts).

This report will employ a similar classification, although instead of distinguishing between 'financial' and 'non-financial' costs, the categories referred to will be:

- direct costs
- other tangible costs
- intangible impacts.

Intangible impacts include the loss in wellbeing that can arise as a consequence of the condition (often referred to as the 'burden of disease'). While these impacts are not necessarily tangible, attempts are still made to ascribe a dollar value to them, although this is extremely difficult. It is therefore important to separate these impacts from 'other' costs such as productivity losses, as these other costs are tangible and have a direct economic impact that is more readily quantifiable.

3.2.3 Total or incremental costs

Some cost of illness studies estimate the total expenditure on the condition, for example, the total healthcare expenditure incurred by or on behalf of people with the condition in a given year. However, this does not recognise that in some areas, a certain level of cost is likely to be incurred irrespective of whether or not a person has ASD. This will be the case in areas such as healthcare and education, although will not

[69] For example refer: Access Economics (2006). The Economic Costs of Obesity, Report by Access Economics to Diabetes Australia.

be the case in areas such as social services, for example, services provided for people with disabilities, such as accommodation support and respite for carers.

An incremental approach seeks to measure the additional costs that arise as a consequence of the condition. An implicit assumption here is that the factor will only be included in the assessment if the cost arising as a consequence of the condition is higher than the cost that would otherwise be incurred. In terms of measuring the incremental impact, it will arise in one of two ways, for example:

1. a cost faced by a person with ASD that is not faced by a person who has normal functioning, for example, expenditure on neuroleptic[70] medication or accommodation support services; or

2. a cost that may be faced by all persons in the community, however the cost faced by a person with ASD is higher, for example, education (children with ASD are more likely to require special education or and/or some form of education support).

In the first case, the total expenditure on the particular good or service can be captured. The second case involves estimating the average expenditure incurred by a person with the condition, and subtracting the average expenditure incurred by someone who does not have the condition.

An incremental approach is considered the most appropriate way to capture the explicit costs of ASD and hence this approach has been adopted in this analysis.

3.2.4 Top-down or bottom up

Cost estimates can be developed in one of two ways. A top-down approach takes total expenditure on a particular service (for example healthcare expenditure) and attributes a certain portion of this to the relevant population. A bottom-up approach estimates the average expenditure per person and then applies this to the relevant population (which may be all people with the condition, or only a sub-set of the population with the condition depending on the need for the particular service).

In most cases a bottom-up approach has been applied here, which is mainly driven by the data limitations. However, a top-down approach is not necessarily always feasible where an incremental approach is being applied. The exception to this is where the expenditure is not incurred by people that don't have the condition, such as social

[70] This medication is used to control potentially psychotic behaviours.

services expenditure, in which case the total expenditure can be apportioned to the subset of the population of service users that have the condition.

More information regarding the approach that has been applied in developing each estimate is provided in section 5.

3.3 Defining the population

3.3.1 Sub-groups

As highlighted previously, autism is a spectrum of disorders, with potential for significant variations in the level of impairment. It is therefore considered important to be able to make some distinction between the different forms of ASD. Ideally, the more the spectrum is disaggregated based on key differences in the nature and level of impairment, the more reliable and robust the analysis. However, not only does this increase the complexity of the analysis, but it is also unlikely to be feasible as there needs to be adequate data available for each sub-group in order to yield reliable results.

The two most common disorders are 'typical' autism and Asperger's, with most of the outcomes literature focussing on one or both of those conditions. In addition, as noted in section 2.1.1, a distinction is often made within the autism category between 'autism' and HFA: the former is the more severe manifestation and is often associated with a degree of intellectual disability. Very different outcomes can therefore be experienced between individuals with this more severe form and those with HFA.

As noted above, the difference between HFA and Asperger's is not necessarily clear; in fact there has been considerable debate surrounding this and whether they are in fact different conditions. While it is beyond the scope of this study to examine this debate in detail, what is important is the extent to which the likely outcomes for a person with HFA differ from a person with Asperger's, as this in turn can reflect differences in costs.

A study by Howlin compared the outcomes for two groups of adults: one with HFA who had shown early language delays and one group who met the diagnostic criteria for Asperger's.[71] The study concluded:[72]

[71] Howlin, P. (2003). Outcome in High-Functioning Adults with Autism and Without Early Language Delays: Implications for the Differentiation Between Autism and Asperger Syndrome. Journal of Autism and Developmental Disorders, 33(1).

[72] Howlin, P. (2003). p.11.

> Overall, the findings indicate that there may be some group differences in the early years (i.e., the symptoms reported by parents at the age of 3). ADI-R algorithm scores, however, suggested that such differences may decrease with age, and in adulthood there were no marked differences between the groups on "Current" ADI-R scores, other ratings of social outcome or standardised tests.

Howlin questioned the distinction between the two conditions, noting also that children with Asperger's may also have markedly impaired language skills.

Irrespective of the diagnostic difference between the two conditions, there is insufficient evidence to suggest that there is a fundamental distinction between the likely outcomes for a person with HFA or Asperger's, at least in the longer-term. While a more detailed mapping of the life trajectory between the two sub-groups may reveal some differences, particularly during childhood, there is insufficient data to do that here (and if such data was available, it would facilitate an incidence-based approach to the costing analysis). In any case, the net impact of this may not be material.

Inclusion of people with HFA with people with autism is likely to overstate the costs of autism, although as will be examined in section 4, outcomes for people at the higher-functioning end of the autism spectrum are not necessarily always better. However, for the purpose of this study HFA and Asperger's have been included in the one category.

3.3.2 Prevalence estimates

As noted above, the prevalence estimates that have been adopted are based on the most recent Australian study by McDermott et al, which suggests a prevalence of:

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

It is assumed that these prevalence estimates remain applicable into adulthood.

Where a distinction can be made between autism and Asperger's/HFA, it is assumed that 75% of the autism group has some form of intellectual disability (refer section 2.1.2). The remaining 25% are assumed to be high functioning and have therefore been removed from this category and included with the Asperger's sub-group.

Other specific assumptions underpinning each cost estimate are provided in section 5.

4 Outcomes and cost implications

4.1 Outcomes for individuals with ASD

The outcomes for individuals with ASD are highly variable. This section will summarise a number of studies that have sought to assess these outcomes. This can then be used to identify the key cost drivers for ASD.

4.1.1 General Outcomes

A Swedish study by Billstedt et al (2005) claims to be the first "long-term epidemiological perspective on the longitudinal natural outcome of autism".[73] They followed a group of 120 individuals for 13 to 22 years until the age of 17 to 40 (the ratio of autism to atypical autism in the sample was 2.4:1). The outcomes for 108 individuals were ultimately included in the study.[74]

Most participants that were originally classified with ASD still met the clinical criteria at the time of follow up. Overall, 57% had a very poor outcome (there was no significant difference across the autism sub-groups), 21% had a poor outcome, 13% had a restricted but acceptable outcome, 8% had a fair outcome and 0% had a good outcome.[75]

Howlin et al (2000) compared 19 adults with autism with 20 adults with developmental language disorders.[76] On nearly all the outcome measures, the adults with autism functioned more poorly, although often the differences were small. They reported that:

- 15.8% had close friends, compared to 26.3% of the adults with language disorder;
- none of the adults with autism had married (compared to four in the other group);

[73] Billstedt, E., Gillberg, C., & Gillberg, C. (2005). Autism After Adolescence: Population-based 13- to 22-year Follow-up Study of 120 Individuals with Autism Diagnosed in Childhood. Journal of Autism and Developmental Disorders, 35(3), p.352.

[74] The measures used were: *Good outcome*: (a) employed or in higher education/vocational training, and (b) if over the age of 23 years, living independently, if 22 or younger, having 2 or more friends/a steady relationship; *Fair outcome:* either (a) or (b) under good outcome; *Restricted but acceptable outcome:* neither (a) or (b) under good outcome, and not meeting criteria for a major psychiatric disorder, other than autism related – they have however been accepted by a group of peers or personnel to the extent that their handicaps are not as readily obvious; *Poor outcome:* obvious severe handicap, no independent social progress, some clear verbal or non-verbal communication skills; *Very poor outcome:* obvious very severe handicap, unable to lead an independent existence of any kind, no clear verbal or non-verbal communication.

[75] Billstedt, E., Gillberg, C., & Gillberg, C. (2005). p.355.

[76] Howlin et al (2000) in Seltzer, M., Shattuck, P., Abbeduto, L., & Greenberg, J. (2004).

- individuals with autism were less likely to be living with their parents (31.6% versus 65% in the other group) and more likely to be living in residential care;
- 5% were working (compared to 60% in the other group); and
- based on reports from parents, 72% of the individuals with autism were not able to function independently in terms of basic living skills, compared to only 10% in the other group.

Seltzer et al (2004) summarised a number of studies of adults with ASD and noted the significant variation in outcomes that can be observed.[77] They cited a series of studies by Rutter et al (1967), Rutter & Lockyer (1967) and Rutter (1969), which followed 63 individuals aged 16 and over that were originally diagnosed in the 1950s and 1960s.[78] Only two of the group gained employment and most lived with their parents or in a hospital or residential community. 14% were considered to have made a good social adjustment, while 25% were rated fair and 61% rated poor. The outcomes were summarised as follows:[79]

> …long-term follow-up studies indicate that there is considerable heterogeneity in social role attainment outcomes for persons with autism. Few adults with autism live independently, marry, go to college, work in competitive jobs, or develop a large network of friends. The majority remain dependent on their families or professional service providers for assistance with tasks of daily living. Even among those who work, jobs are often poorly paid and do not provide a living wage. Furthermore, adults with autism tend to have poorer outcomes than others with disabilities. However, there is a subgroup of between 15 and 25% of adults with autism who show more favourable outcomes.

A study by Barnard et al (2001) surveyed approximately 450 parents of adults with ASD in the UK.[80] This revealed that 49% of adults with autism and Asperger's were still living at home with their parents and over one-third were in residential care. 70% of parents surveyed believed their son or daughter could not function independently without support (these individuals were across the range of the autism spectrum):[81]

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77 Seltzer, M., Shattuck, P., Abbeduto, L., & Greenberg, J. (2004).

78 Seltzer, M., Shattuck, P., Abbeduto, L., & Greenberg, J. (2004). p.240.

79 Seltzer, M., Shattuck, P., Abbeduto, L., & Greenberg, J. (2004). p.240.

80 Barnard, J., Harvey, V., Potter, D., & Prior, A. (2001). p.16.

81 Barnard, J., Harvey, V., Potter, D., & Prior, A. (2001).

> In their parents' opinion less than 10% of adults can manage basic tasks without help – preparing meals, housework, paying bills, managing money, shopping, laundry and dealing with letters.

Of the adults surveyed in this study, only 6% of people with autism were in full-time employment, with 4% in part-time.[82] 24% were 'doing nothing' or 'helping around the house'.

Nearly one-third of the people with ASD were not involved in any social activities.[83] This was higher for teens and those with Asperger's syndrome (37%). The study also revealed significant mental health issues:[84]

> A third (32%) of parents said their son or daughter had already experienced mental ill health – and where diagnosis was late this rose to 45% of those diagnosed in their 20s, and 50% of those diagnosed after the age of 30…Of those experiencing mental ill health, 56% suffered with depression, a further 11% suffered nervous breakdown or near nervous breakdown, and 8% felt suicidal or had attempted suicide.

Stein et al (2001) reviewed the outcomes for a group of adults diagnosed with severe autism in childhood.[85] The group of 25 adults, aged from 20 to 36, had all required prolonged hospitalisation and all were currently hospitalised. 82% had social interaction impairments, 61% had communication disturbances and 50% had restricted and stereotyped movements and behaviours. 96% had not developed peer relationships, 86% showed an absence of social or emotional reciprocity and 58% had an absence of spoken language. The social impairment was the most severe.

Only one patient had an IQ in the low range of normality, with three patients demonstrating moderate intellectual disability and 18 having severe intellectual disability. 75% of patients require neuroleptic treatment.

A study by Kobayashi, Murata and Yoshinaga (1992) revealed more positive results for a group of 201 young adults with autism in Japan, although outcomes were still mixed.[86] The present language developmental level was rated as very good in 16.2% of

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82 Barnard, J., Harvey, V., Potter, D., & Prior, A. (2001). p.18.

83 Barnard, J., Harvey, V., Potter, D., & Prior, A. (2001). p.20.

84 Barnard, J., Harvey, V., Potter, D., & Prior, A. (2001). p.22.

85 Stein, D., Ring, A., Shulman, C., Meir, D., Holan, A., Weizman, A. & Barak, Y. (2001). Brief Report: Children with Autism as They Grow Up – Description of Adult Inpatients with Severe Autism. Journal of Autism and Developmental Disorders, 31(3).

86 Kobayashi, R., Murata, T. & Yoshinaga, K. (1992). A Follow-up Study of 201 Children with Autism in Kyushu and Yamaguchi Areas, Japan. Journal of Autism and Developmental Disorders, 22(3).

the group, good for 30.5%, fair for 32%, poor for 9.1% and very poor for 12.2%.[87] The present adaptive functioning levels were rated as: 10.7% very good; 16.2% good; 26.9% fair; 22.8% poor; and 23.4% very poor.[88]

Deterioration of the condition during adolescence was noted in 47 of 149 cases (the balance were unknown), with symptoms including hyperactivity, regression, aggressiveness, destructiveness and increased obsessive or repetitive behaviours. Other outcomes noted include:

- at age 12, 52 were in an "ordinary" class (with the balance in a special class or school);
- 41 were employed, with another two helping with the family business; and
- 36 suffered epilepsy.

A study by Eaves and Ho (2008) followed a cohort of children born between 1974 and 1984 into young adulthood.[89] At the time the outcomes were assessed the group had a mean age of 24 years. 48 families participated in the final assessment.

Approximately half of the group had a good to fair outcome with 46% recording a poor outcome. Comorbid conditions, obesity and medication use were found to be common with families noting unmet needs, particularly in social areas. The main outcomes from the study included the following:

- 62.5% of individuals reported having general emotional difficulty, while 50% were thought to have OCD and 50% had anxiety;
- 33% could not read and 23% read at grade 9 to 13 level. 35% had no writing skills and 13% were at a high school level;
- almost 30% attended post-secondary education, with none of the individuals receiving a certificate of completion or degree;
- 56% had been employed, mostly in volunteer, sheltered or part-time work averaging five hours per week. Only two individuals worked independently with

[87] *Very good*: can communicate freely with a rich vocabulary; *good*: can communicate, but unnaturally and sometimes inappropriately; *fair*: can understand others in daily life, but cannot communicate verbally; *poor*: vocalized echolalic speech mostly in single words; *very poor*; vocalizes 'words' of no meaning, or does not talk.

[88] *Very good*: employed (or goes to school) and adapts satisfactorily, his/her ability to work is highly estimated; *good*: employed (or goes to school), lives a normal life almost independently; *fair*: behaves a little inappropriately but lives a daily life at home, or not employed but lives a daily life with little aid; *poor*: behaves very oddly, cannot adapt socially and needs some aid; *very poor*: has poor social skills, cannot adapt socially, always needs much aid.

[89] Eaves, L. & Ho, H. (2008). Young Adult Outcome of Autism Spectrum Disorders. Journal of Autism and Developmental Disorders, 38(4), pp 739 – 747.

one supporting himself. 79% received the government disability pension and had a social worker;

- 56% lived with their parents and 35% were is supported arrangements such as group homes, foster care or managed in-home care. Four individuals (8%) lived more or less independently;
- 42% had difficulty maintaining personal hygiene and only 35 to 45% were able to shop, prepare meals or do housework independently. 54% had difficulty managing daily life;
- 33% were reported to have at least one selective friendship with almost 30% attending a social, church or club regularly; and
- parents rated quality of life at 5.2 on a one to ten scale with 79% reported to have good to excellent health.

A 2009 study by Andrew et al compared the adult psychosocial outcomes of children with specific language impairment (SLI), pragmatic language impairment (PLI) and ASD.[90] The key outcomes from the study were as follows:

- participants in the SLI group were most likely to pursue vocational training and work in jobs not requiring a high level of language/literacy ability;
- the PLI group obtained higher levels of education and worked in 'skilled' professions;
- the ASD participants had lower levels of independence and more difficulty obtaining employment; and
- all groups had problems establishing social relationships, but these difficulties were most prominent in PLI and ASD groups.

A Spanish study by Saldana et al (2009) surveyed 74 families on objective Quality of Life indicators such as employment, health, adaptive behaviour and social networks.[91] The study group had a mean age of 24.6 years with 85% being male. Most of the individuals had received diagnoses of autism (65%) or Asperger's (10%) with the remainder labelled generically as persons with PDDs or ASDs.

[90] Andrew, J., et al (2009). Research Report: Adult Psychosocial Outcomes of Children with Specific Language Impairment, Pragmatic Language Impairment and Autism. International Journal of Language and Communication Disorders, 44(4), pp 511 – 528.

[91] Saldana, D., et al (2009). Objective and Subjective Quality of Life in Adults with Autism Spectrum Disorders in Southern Spain. Autism, 13(3), pp 303-316.

The quality of social interaction, as measured using the DAS disability scale, was extremely poor, with 49% of adults initiating most social interactions aimed at satisfying personal needs. 15% displayed social interactions appropriate to their mental age. Only 29% of individuals engaged in spontaneously initiated activities.

87% of the group lived with their parents. For 7% of participants, their mothers represented the only member of their social network. In 34% of cases, individuals had only two people in their social network. Friends accounted for 9% of the individuals' social networks.

Only 16% of participants were not receiving any support services, with 64% receiving one type of service, 19% receiving two types of services and one individual receiving three types of services. Other observations included:

- 14 individuals lived in a residential institution for severely disabled persons;
- 9.4% of the individuals living at home were receiving support at home;
- 19% of the families with a person with ASD at home were benefiting from some form of family relief program; and
- 92% of the participants were receiving disability financial benefit.

Liptak et al (2011) sought to describe social participation, and identify the factors affecting it, in a sample of older youth and young adults with autism.[92] The mean age at the end of the study was 19 years. The outcomes reported included the following:

- 82.6% lived with their parents;
- 34.4% had little trouble conversing, 38.9% had much trouble, and 14.2% do not converse;
- 74.8% never use instant messaging, chat rooms or email;
- 55.4% had never met up with friends in the previous 12 months, 16% sometimes had but not every week; and
- 63.9% had not received phone calls from friends in the previous 12 months and 20.3% had but less than once a month.

The study therefore found that most individuals were socially isolated, although did not consider if more social interactions would be desired. It also observed specific

[92] Liptak, G., Kennedy, J. & Dosa, N. (2011). Social Participation in a Nationally Representative Sample of Older Youth and Young Adults With Autism. Journal of Development and Behavioural Pediatrics, 32(3), April.

patterns of related factors, such as socio-economic status, the severity of the condition (due to comorbidities) and the ability to communicate.

4.1.2 Outcomes for Adults with High Functioning Autism

Howlin (2000) examined outcomes in adulthood for more able individuals with autism or Asperger's syndrome.[93] The findings from a number of other studies are summarised, including:

- Kanner (1993). The study was based on 93 individuals in their 20s and 30s who the author had originally seen as children. Most remained highly dependent and a number were in institutions. Eleven had jobs and one was at college. Seven had their own home and one was married with a child. The rest lived at home. Many belonged to social groups however "few had any close or intimate relationships."
- Tantum (1991). Tantum examined 46 adults with an average age of 24. More than 90% had ongoing problems with communication. Only two had college education and four were in jobs. Just under 50% lived at home and 53% were in residential care. Over 40% had neurological problems and around one-third met the criteria for psychiatric illness.
- Szatmari et al (1989). This study examined 26 adults with normal IQ. Around 50% had received special schooling and the balance had been to college or university, with 44% graduating.

Social initiations were described as 'clumsy' in 40 percent; one-third had problems in conversation and two-thirds had overly formal speech. On the whole impairments were greater on non-verbal than verbal items.[94]

Overall, the study did demonstrate that substantial improvements could be made for children with autism without intellectual disabilities over time.

- Venter et al (1992) and Lord and Venter (1992). These studies examined 58 high-functioning children, 22 of which were aged over 18 at the time of the study. Overall this group had performed less well academically compared to the group examined by Szatmari et al. One had completed a degree. Eight were living at least semi-independently. Twelve remained employed, although in relatively low level positions. There was little change in IQ over time.

[93] Howlin, P. (2000). Outcome in Adult Life for More Able Individuals with Autism or Asperger Syndrome. Autism, 4(1).

[94] Howlin, P. (2000).

- Howlin et al (2000) and Mawhood et al (2000). These studies examined 19 young men with high-functioning autism. Only three were considered to have achieved a good outcome. Two were moderately impaired and 14 "continued to show substantial impairments".

- Goode et al (1999). This study examined outcomes for 75 people aged 21 or over who had been assessed prior to age 16. One-third had attended specialist schools for children with autism and 19% had largely been in 'mainstream' schools. Seven were in regular employment and one was self-employed. Two others worked as volunteers. 25% were in sheltered employment and almost half were in day or residential centres. Three lived independently. Over 50% lived at home and 26% were in residential accommodation. Almost 50% reported having no friends. Overall, just over 25% could be considered to have achieved a 'good' or 'very good' outcome.

A comparison across all of the studies highlights the range of outcomes achieved. Howlin comments:[95]

> Despite the groups being apparently relatively homogeneous the results are extremely variable. Thus, the proportion in work ranges from 5 to 44 percent; the proportion living independently from 16 to 50 percent; assessments of 'good' outcome from 16 to 44 percent; and rates of psychiatric disturbance from 11 to 67 percent.

Jennes-Coussens, Magill-Evans and Koning (2006) compared a group of twelve young men with Asperger's with a group of thirteen young men without Asperger's (the mean age of both groups was 20).[96] Overall, the participants with Asperger's rated their quality of life lower than the group without. Other observations included:

- many of the men with Asperger's described academic problems;

- one-third of the group with Asperger's were neither working or going to school, unlike any of the group without Asperger's;

- the number of men living at home with family was similar between the two groups, although four of the men with Asperger's indicated that they were unable to live independently because they could not manage certain daily tasks; and

[95] Howlin, P. (2000). pp.72-73.

[96] Jennes-Coussens, M., Magill-Evans, J. & Koning, C. (2006). The Quality of Life of Young Men with Asperger Syndrome. Autism, 10(4).

- social well-being was rated considerably lower for the men with Asperger's. They also rated their physical and psychological health lower than the other group. A number of the group had suffered from depression and anxiety.

Loynes (2001) observed that people with ASD generally have difficulties holding down permanent employment due to their lack of social skills, even if they are well qualified, which is often the case for individuals at the higher-functioning end of the spectrum, including those with Asperger's.[97] While the individual may derive some benefit from participating in training, they will not necessarily be able to utilise the skills they have acquired. A study by Howlin and Peacock (1996) is cited, which found that:[98]

> …most supported employment schemes which are in place to address this problem tend to concentrate on low level unskilled jobs, which are not suitable for the complex needs of people with Asperger Syndrome who may have very good qualifications.

Grandin (1999) notes the importance of determining the 'right' job that makes the best use of the strengths and capabilities of a person with ASD.[99]

The study by Barnard et al (2001) highlights that while it is often assumed that people with higher functioning autism can manage independently, this is not necessarily always the case. Their study revealed that, of people with Asperger's:[100]

- only 3% are living independently
- 59% are living with their parents
- only 12% were in full-time employment, with 6% in part-time
- over 50% need help managing money and paying bills
- 40% need help preparing a meal.

These authors also noted that a significant number of adults would be capable of living independently with only a few hours of support per week, but are currently not doing so.

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97 Loynes, F. (2001). p.29.

98 Loynes, F. (2001). p.30.

99 Grandin, T. (1999). Choosing the Right Job for People with Autism or Asperger's Syndrome. Colorado State University, http://www.autism.org/temple/jobs.html.

100 Barnard, J., Harvey, V., Potter, D., & Prior, A. (2001). p.17.

To maximise opportunities for adults with high-functioning autism, support in terms of education, living arrangements and social support networks is required.[101] However, as noted by Barnard et al (2001), access to services can be more difficult for those with higher functioning autism. For example, adults in the UK will be ineligible for Learning Disability Services if their IQ is over 70, notwithstanding the social and communication difficulties they may have. The adults at the higher end of the spectrum in this study cited employment as their single biggest barrier, with 50% not in work and all but two wanting paid employment.[102] The frustrations this can cause can often lead to other problems, such as depression.

Another perspective on this is provided by Grandin, who notes concerns that intellectually gifted children with HFA or Asperger's can be denied opportunities by virtue of this 'label'.[103] For example, they may not gain access to supports and facilities provided to other intellectually gifted children that don't have HFA or Asperger's, or be pointed in a direction that will allow their capabilities to be fully maximised.

Finally, it has been postulated that individuals with ASD have a higher propensity to become involved in criminal activity. Loynes cautions against overstating the link between ASD and crime:[104]

> It is widely believed that offending rates are in fact low, if not lower than for the general population due to the particular affection for rules which most people with autism or Asperger syndrome display.

Howlin notes that there is limited evidence of above-average crime rates for people with ASD:[105]

> However, isolated incidents of offending, often related to obsessional tendencies or impaired social understanding, have been reported.

A literature review by Ghaziuddin et al (1991) was undertaken to detect any evidence of a link between Asperger's and crime however the results did not support the proposition that people with Asperger's are more prone to committing violent acts than the rest of the population.[106]

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101 Howlin, P. (2000). p.79.

102 Barnard, J., Harvey, V., Potter, D., & Prior, A. (2001). p.18.

103 Grandin, T. (2001). Genius May be an Abnormality: Educating Students with Asperger's Syndrome, or High-functioning Autism. Colorado State University, http://www.autism.org/temple/genius.html.

104 Loynes, F. (2001). p.29.

105 Howlin, P. (2000). p.76.

106 Ghaziuddin, M., Ghaziuddin, N. & Tsai, L. (1991). Brief Report: Violence in Asperger Syndrome, A Critique. Journal of Autism and Developmental Disorders, 21 (3).

Overall, therefore, there is insufficient evidence to suggest that a person with ASD has an increased likelihood of being engaged in criminal activity.

4.1.3 Conclusions

Overall, the studies reveal considerable variation in the spectrum of functioning associated with ASD, which will ultimately manifest in a range of outcomes achieved by people with ASD into adulthood. Caution needs to be exercised in comparing results across the various studies given differences between the sample groups in each study (there can also be considerable heterogeneity within the sample itself), as well as differences in the outcomes measures used and methodologies employed.

Seltzer et al's conclusion on the trajectory of development for adolescents and adults with ASD is as follows:[107]

> …although there has been only a small amount of research, fraught by many methodological limitations, describing the life course manifestation of autism, some consistent findings have emerged. It appears that modest improvement in symptoms is evident, as least in some individuals, from childhood to adolescence and into adulthood. However, this improvement seldom leads to levels of functioning in the normal range, which reinforces the notion that autism is generally a lifelong condition. Moreover, improvement is not seen for all behaviours and not all individuals improve. Some individuals even decline, especially if they are very low functioning, have very severe symptoms, or develop seizures.

As noted above, a consistent conclusion that has been drawn by a number of studies is that IQ is an important predictor of outcomes and for those with a lower IQ it can be difficult to determine whether outcomes are a function of an individual's ASD or their IQ.

While a number of people with higher IQs achieve very good outcomes, a number of studies of higher-functioning groups showed that some still achieved relatively poor outcomes despite having a higher IQ. Barnard et al observe:[108]

> The medical terminology 'high', 'medium' or 'low' functioning autism is not an indicator of the individual's ability to live an independent life. An understanding of language and above average IQ can mask high levels of vulnerability and need.

[107] Seltzer, M., Shattuck, P., Abbeduto, L., & Greenberg, J. (2004). p.245.

[108] Barnard, J., Harvey, V., Potter, D., & Prior, A. (2001). p.24.

This can also suggest, as noted by Grandin, that individuals may need to be pointed in a direction that enables that person to maximise their strengths and capabilities.

It is also evident that adolescence can be a critical period for people with ASD, with a number developing secondary mood disorders. This was highlighted in the study by Kobayashi, Murata and Yoshinaga (1992), with 47 subjects in the group experiencing significant deterioration during this period.

4.2 The Outcomes for Families

4.2.1 General impacts

Caring for a child or adult with ASD can have a significant impact on the family, which can result in additional direct costs to the family as well as broader societal costs. In addition to the time and resources that may be required to provide care, the symptoms exhibited by an individual with ASD can result in higher levels of stress in the family environment. Loynes observes:[109]

> Families of people with autism often struggle with the emotional and physical effort of living with someone who may have complex and challenging behaviour, leading to a lack of sleep, and a significant degree of social exclusion. This is commonly exacerbated by a 'battle' with professionals for diagnosis and services. These difficulties are often accompanied by significant financial costs.

This can result in physical and mental health problems as well as marital stress and in some cases family breakdown.

In 2002, Gray published a ten year longitudinal study on the impacts of ASD on other family members.[110] The results demonstrated that families experienced higher stress levels in the early period, just after the initial diagnosis, and then again in the early years of adulthood, when individuals with ASD may have difficulties achieving living independence (as noted in the outcomes studies reviewed above, many adults do not achieve this independence).

Gray's study reported that over half of the parents experienced high levels of stress, anxiety and depression as a result of their family member's symptoms and behaviour, with approximately one-third receiving medication or psychotherapy as treatment for their condition. The study also indicated that anxiety over the family member's future

[109] Loynes, F. (2001). p.10.

[110] Gray, D. (2002). Ten Years On: A Longitudinal Study of Families of Children with Autism. Journal of Intellectual and Developmental Disability, 27 (3).

and concerns over the existence of violent tendencies become more prominent causes of stress in family members as time progresses.[111]

Hastings et al (2005) noted that stress levels are generally higher in mothers than in fathers, which may be due to the adoption of different coping strategies.[112] Sharpley et al (1997) identified the three most significant sources of stress as:[113]

> (1) the permanency of the condition; (2) the lack of acceptance of autistic behaviour by society and family members; and (3) the low levels of support provided by health care services and other social services.

It is also widely reported that the rate of marital stress, including marriage breakdowns, is higher amongst families of individuals with ASD, which in turn, can lead to poor physical and mental health. Barnard et al note that this stress can be exacerbated by delays in diagnosis and/or access to support services.

Higgins, Bailey and Pearce (2005) observe that caring for a child with ASD impacts not only on the caregiver but also other siblings.[114] Parents tend to have less time for other family members. Ongoing dependency, financial difficulties and limits on family activity also impose stress. A study by Ross and Cuskelly (2006) concluded that higher levels of stress in families with a child with ASD implied a slower rate of development of social skills in other siblings.[115] The presence of aggression in children with ASD was reported as the prominent concern by 84% of the siblings surveyed.

The study by Higgins, Bailey and Pearce surveyed 134 families caring for children with ASD in rural and regional Victoria (40% responded to the survey). The main area of concern reported by caregivers in the survey was aggressive behaviour exhibited by 62% of the children. Misbehaviour in public was another key source of stress, which is also based on concerns regarding community perceptions. Marital happiness of primary caregivers was lower than the mean rating obtained from the 'norm group' (being 407 married couples from four American states in a 1983 study by Norton). Family adaptability and cohesion were also below the mean for the norm group. They found:[116]

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111 Gray, D. (2002).

112 Hastings, R., Kovshoff, H., Brown, T., Ward, N., Espinosa, F., & Remington, B. (2005). Coping Strategies in Mothers and Fathers of Preschool and School-Age Children with Autism. Autism, 9(4), p.378.

113 Sharpley et al (1997), cited in Higgins, D., Bailey, S., & Pearce, J. (2005). Factors Associated with Functioning Style and Coping Strategies of Families with a Child with an Autism Spectrum Disorder. Autism, 9(2), p.126.

114 Higgins, D., Bailey, S., and Pearce, J. (2005).

115 Ross, P. & Cuskelly, M. (2006). Adjustment, Sibling Problems and Coping Strategies of Brothers and Sisters of Children with Autistic Spectrum Disorder. Journal of Intellectual & Developmental Disability, 31 (2).

116 Higgins, D., Bailey, S., & Pearce, J. (2005). p.132.

> Caregivers acknowledged the high level of stress on families, with 41 percent reporting some form of physical, emotional, financial or marital relationship stress. Some caregivers (25 percent) described a negative effect on family life…There also appeared to be a lack of understanding about ASD from the wider community, with 22 percent of caregivers stating that family, friends, teachers and the community did not understand the behavioural characteristics of children with ASD.

Overall, this particular study confirmed the hypothesis that primary caregivers of a child with ASD had lower marital happiness, family adaptability and family cohesion:[117]

> …the average family in the sample falls outside the healthy family functioning range, with families demonstrating less flexibility and a lack of warmth and connection compared with normative data.

It has been noted that mothers of children with ASD tend to have higher stress levels, with almost half estimated to be in the 'critical' range:[118]

> The mothers experienced more symptoms of stress than parents of children with other disabilities such as severe learning disabilities and Down's syndrome, and parents of normally developing children.

A similar finding was reported by Seltzer et al:[119]

> Mothers and fathers of children with autism have consistently been found to exhibit higher levels of stress, more mental health symptoms, and more marital discord compared with parents of children with Down syndrome, fragile X syndrome, cystic fibrosis, behaviour disorders, intellectual disability of unknown etiology, and typically developing children…Furthermore, the mothers in the autism group also displayed significantly higher levels of depressive symptoms.

While most studies of families have tended to focus on carers of children with ASD a study by Hare et al (2004) examined families caring for adults with ASD.[120] The study involved interviews with 26 parents of adults with ASD (mostly mothers) in the UK.

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117 Higgins, D., Bailey, S., & Pearce, J. (2005). p.133.

118 Warfield, M. (2005). Family and Work Predictors of Parenting Role Stress Among Two-Earner Families of Children with Disabilities. Infant and Child Development, 14, p.14.

119 Seltzer, M., Shattuck, P., Abbeduto, L., & Greenberg, J. (2004). p.244.

120 Hare, D., Pratt, C., Burton, M., Bromley, J. & Emerson, E. (2004). The Health and Social Care Needs of Family Carers Supporting Adults with Autistic Spectrum Disorders. Autism, 8(4).

Parents indicated that aggression was the most challenging behaviour, including physical attacks on family members. 46% of participants indicated that "they wished that the diagnosis had been made earlier to obviate current problems."[121] 50% received the diagnosis before age 15, while others did not receive the diagnosis until late teens, late 20s or early 30s.

Many families had to move house due to reasons associated with ASD (for example, moving away from a main road). 28% of participants were above the threshold level on the General Health Questionnaire, indicating issues with their own mental health. The impact of stress was that it tended to "reduce not only the capacity to care, but also the ability of carers to negotiate effectively with the service systems and to take and act on advice."[122]

Most felt they had no support from social groups, religion, parents' groups, co-workers or other parents. Friends were often 'not available', which was revealed to reflect a concern with burdening friends with concerns. Most support was sourced from agencies, day centres, and their own children. Awareness of services was high, but usage was low:[123]

> Resources such as parents' groups and national support groups were not well utilised, with parents often stating that they used these when the family member with ASD was a child.

In summarising the outcomes of their study:[124]

> The majority of participants expressed some form of restriction on their lives, predominantly the limitations of their social lives, describing their circumstances as 'having no life', being 'grounded for 20 years', 'feel like a prisoner' or 'can't live a normal life'. Restrictions on where the families could live were also significant in the interviews…Some participants discussed the impact that living with someone with autism had on other relationships, primarily with their partners and other children. While several parents said that they would be unable to cope without support from their partner, others believed there had been a detrimental effect on their relationship.

Most participants expressed concerns about the future of the person in their care.

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121 Hare, D., Pratt, C., Burton, M., Bromley, J. & Emerson, E. (2004).

122 Hare, D., Pratt, C., Burton, M., Bromley, J. & Emerson, E. (2004). p.441.

123 Hare, D., Pratt, C., Burton, M., Bromley, J. & Emerson, E. (2004). p.434.

124 Hare, D., Pratt, C., Burton, M., Bromley, J. & Emerson, E. (2004). p.438.

Benson and Kersh (2011) undertook a two year longitudinal study of families with children with ASD, examining the impact of marital quality on three indicators of maternal psychological adjustment, being depressed mood, parenting efficacy and subjective well being.[125] They found that 26% of mothers reported baseline scores in the "distressed" range of marital quality. It was also found that marital quality was negatively associated with child problem behaviour.

4.2.2 Employment

In terms of the economic and financial impacts that ASD has on family members, the effects on the mother tend to be the most significant. This is because in the majority of cases, the mother is the primary care-giver. In a UK-based study by Curran et al (2001) of 16 families of children with autism, 12 of the 16 mothers were found not to be in paid employment.[126] A population-based survey showed that 60-70% of mothers returned to the workforce after having a child, compared with just 25% from the sample of mothers with children with autism.[127]

As part of this study seven of the families submitted surveys on the additional expenditure that could be attributed to supporting their child. The families covered 40%of this expenditure, with the remainder being covered by various charity donations and the Disability Living Allowance.[128]

Warfield noted that obtaining and maintaining employment is more difficult for mothers of children with special needs.[129] Mothers of children with special needs who work tend to have to miss more days at work, and many eventually have to reduce their hours of work or leave the workforce altogether, with limited reliable sources of childcare available. At the same time, employment can also be a source of respite for mothers of children with disabilities.

Warfield's study examined 51 dual-income earning households who were enrolled in the Early Intervention Collaborative Study in the US. From the group of mothers reporting greater interest in their work, those with children with more behaviour problems reported greater parenting role stress than those with children with fewer behaviour problems.

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125 Benson, P. & Kersh, J. (2011). Marital Quality and Psychological Adjustment Among Mothers of Children with ASD: Cross-Sectional and Longitudinal Relationships. Journal of Autism and Developmental Disorders, February.

126 Curran, A. et al. (2001). Time Costs of Caring for Children with Severe Disabilities Compared with Caring for Children Without Disabilities. Developmental Medicine & Child Neurology, 43 (8).

127 Curran, A. et al. (2001).

128 Curran, A. et al. (2001).

129 Warfield, M. (2005).

Limited child care services for children with serious behaviour problems, however, constrained the employment options for some mothers such that they were forced into jobs that they viewed as less desirable or less career-oriented and that under-utilised their skills and training…when employed mothers cannot pursue a meaningful work life, they miss out on the benefits of having an interesting job.[130]

In the study by Hare et al of carers of adults with ASD, most participants were full-time carers, although five worked full-time and three worked part-time.[131] A majority received less than the average weekly income, with 43% earning less than £200. However, many of the parents in the study were retired.

The impact of caring responsibilities on employment is examined further in section 5.

4.3 Mortality

Comparative mortality studies that have recently been undertaken in the US have demonstrated that individuals with ASD do have a reduced life expectancy when compared to the general population.

A Californian study of over 11,000 people with ASD clearly showed that individuals with ASD carry an increased mortality risk with a Mortality Ratio (MR) of 213% (this is the ratio of observed deaths to expected deaths).[132] It is important to note that the MR was significantly higher for females (490%) than it was for males (167%). These ratios convert to a reduction in the life expectancy of a 5 year old boy by 6.1 years and a girl of the same age by 12.3 years.

Another measure of mortality that allows for accurate comparison between the subject group and the general population is the standardised mortality ratio (SMR), which compares the death rate in the subject population with the death rate expected in the general population. Individuals with ASD exhibited a SMR of 2.4, meaning that they carry more than double the mortality rate of the general population.[133] Again the rate for girls was far higher than the corresponding ratio for boys – 5.5 and 1.7 respectively.

These statistics are further supported by the results of a 24 year survey that was recently concluded by Isager, Mouridsen and Rich.[134] This study involved tracing 341

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130 Warfield, M. (2005). p.167.

131 Hare, D., Pratt, C., Burton, M., Bromley, J. & Emerson, E. (2004).

132 Shavelle, R., Strauss, D. & Pickett, J. (2001). Causes of Death in Autism. Journal of Autism and Developmental Disorders, 31 (6).

133 Shavelle, R., Strauss, D. & Pickett, J. (2001).

134 Isager, T., Mouridsen, S. & Rich, B. (1999). Mortality and Causes of Death in Pervasive Developmental Disorders. Autism, 3 (1).

children with various PDDs for a 24 year period. During this period of time 12 subjects died, giving an overall mortality rate of 3.5% and a SMR for the entire sample group of 1.9. However, when ASD was isolated from the rest of the PDDs a SMR of 3.4 was obtained.

Research indicates that the most influential factor in relation to ASD and mortality rates is the level of intellectual disability. The study by Shavelle et al revealed a SMR for individuals with no or very low levels of intellectual disability of 1.4, compared with 3.1 for those with higher levels of intellectual disability.[135]

For individuals with no or low levels of intellectual disability seizures represented a very prominent cause of death with a SMR of 22.6. This sample group also exhibited higher SMRs than the general population in relation to circulatory diseases (2.3), congenital anomalies (2.0), cancer (1.9) and nervous and sensory diseases (4.8). Among the external causes of death, drowning (3.9) and suffocation (5.7) carried the largest SMRs for those individuals with ASD with no or low levels of intellectual disability.[136]

For individuals with higher levels of intellectual disability the SMRs were higher in almost all categories than for the general population and most were higher than the SMRs for individuals with ASD and no or low levels of intellectual disability. Seizures were again the most significant statistic, carrying a SMR of 36.9, far greater than the SMR for those without an intellectual disability (22.6). Other major causes of death for the individuals with higher levels of intellectual disability included drowning, with a SMR of 13.7 and suffocation, which carried a SMR of 51.4, almost ten times the equivalent rate for individuals without intellectual disability.[137]

Overall, the evidence from these studies suggests that ASD carries a higher mortality rate than the normal population. However, it is possible that this could largely be a function of comorbid conditions (particularly epilepsy), rather than ASD itself.

4.4 Cost implications

4.4.1 Outcomes for people with ASD and their families

The previous review identifies a number of possible outcomes for people with ASD, recognising that there will be considerable variation in impacts between individuals. In general, they include the possibility of:

[135] Shavelle, R., Strauss, D. & Pickett, J. (2001).

[136] Shavelle, R., Strauss, D. & Pickett, J. (2001).

[137] Shavelle, R., Strauss, D. & Pickett, J. (2001).

Poor physical and mental health. This includes the impact of a range of comorbid conditions that have been associated with ASD, including depression and epilepsy. This will result in increased healthcare expenditure. It could also increase reliance on services such as supported accommodation.

Lower educational attainment. This is particularly the case for those individuals with autism that have an intellectual disability. This may result in children having to attend a special school and/or attend a 'mainstream' school with additional services and supports. This will involve additional costs. In the long-term, it will also adversely impact employment prospects (the consequences of which are considered below) and increase reliance on social services such as community access programs.

Poor employment outcomes. This could manifest in either:

- unemployment; or
- underemployment – for example, many people with Asperger's may be highly skilled however have difficulty finding and/or retaining employment in a role that utilises their full capabilities.

This will result in lower income for the individual (and hence increased reliance on Government welfare) and a reduction in productivity for the economy. It will also increase reliance on social services such as employment support and community access programs.

Limited living independence. This will increase reliance on services such as accommodation support and personal care. Some individuals may also be housed in residential facilities. Many will remain at home and rely on family and/or friends to provide care (this is referred to as 'informal care').

Poor social functioning. Poor social functioning can result in social isolation and can also impact employment outcomes. This in turn could lead to issues with physical and mental health.

Overall, these issues can serve to reduce an individual's well-being and quality of life. They are summarised inTable 2 Table 2.

Table 2 Outcomes for individuals with ASD - summary

Factor	This will mainly impact...	The main cost impacts of this factor are...
Poor physical and mental health: • 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: 1. unemployment 2. underemployment, which is either: • 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.	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

A number of outcomes have also been identified for families who have children or adults with ASD in their care. This includes:

Employment impacts for primary carer. The employment of the primary carer/s may be impacted in a number of ways. For example, some carers may still be able to work but work fewer hours than preferred, or in a role that is not fully utilising their skills and capabilities. Others may have to withdraw from the workforce altogether. This will have similar impacts as identified above. It could also increase financial stress, which in turn can adversely impact relationships and health.

Increased stress. As outlined above, caring for a child or adult with ASD can increase stress for carers, as well as other family members. This in turn can put strain on relationships, increase the risk of family breakdown, and adversely impact physical and mental health.

Social isolation. A number of studies of the impacts of ASD on families identified social isolation as an issue. In addition to the impact on well-being, this in turn can adversely impact physical and mental health.

These outcomes are summarised in Table 3.

Table 3 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) Mental and physical health (eg depression) General well-being	Increased healthcare expenditure
Social isolation	Mental and physical health General well-being	Increased healthcare expenditure

One of the key impacts on the families of people with ASD is financial hardship. This tends to result in an increased reliance in welfare support, which is a transfer effect[138] rather than an incremental cost (transfer effects have not been estimated here). Increased expenditure on services and supports for the family member with ASD will be captured under the costs for the individual. There are also a number of other costs for families that cannot be reliably estimated here, such as the costs of family breakdown. These exclusions are examined briefly in section 6.

4.4.2 Cost categories to be examined

The main cost categories that have been identified are listed below. Overall, the methodology employed has been driven by the availability of data. A conservative approach has been taken in this analysis. Where adequate data could not be sourced, estimates have not been produced at all, although this does not necessarily mean that these costs are not currently being incurred. Costs that have not been able to be estimated in this study are listed at the end of this report.

The categories of costs that will be estimated are:

Direct costs

1. *Increased healthcare expenditure.* This analysis will be limited to expenditure incurred by or on behalf of people with ASD. While possible impacts on families have also been identified, there is insufficient data available to make an assessment of the likely increase in expenditure across the population of families caring for a person with ASD.

[138] A transfer refers to payments that are made between Government and other sectors, such as welfare payments or foregone taxation revenue. Inclusion of these items could result in double-counting.

2. *Social services expenditure.* This includes expenditure on Government-funded services such as accommodation support, employment support and respite for families. While it is likely that individuals and/or their families are incurring other expenditures, which they may need to fund with their own resources, there is no data available to estimate the extent of this across the population of people with ASD.

3. *Increased education expenditure.* The main area that has been examined here is special education expenditure. Insufficient data is available to estimate the other possible costs of additional educational services and supports obtained for children with ASD, including those who do not attend a special school.

Other tangible costs

4. *Employment.* The main impact that will be examined here is productivity. The consequent impact on personal income, and reliance on welfare, is a transfer effect (another such effect is reduced taxation revenue for Government). As noted above, transfers have not been estimated here.

5. *Informal care.* The value or 'cost' of informal care can be considered in a number of ways (as examined in section 5.5), one of which is to estimate the foregone productivity arising from the carer's reduced participation in the workforce. As noted above, the reliance this may place on welfare payments is a transfer effect.

Intangible impacts

6. *Quality of life.* An attempt can be made to attribute a cost to the reduction of the quality of life for the individual (there is no data available to do this for family members). Mortality will also be considered here. This methodology is examined in more detail in section 5.6.

We have not reviewed the potential costs associated with comorbid conditions. This is because at least some of these costs will be already reflected in the incremental costs incurred by people with ASD.

More information regarding the methodology and assumptions underpinning the analysis are examined in the following section. Costs that have not been captured are outlined briefly in section 6.

5 Cost estimates

5.1 Healthcare expenditure

People with ASD are likely to have a physical and mental health issues that will require ongoing expenditure from childhood through to adulthood. The potential costs of comorbid conditions will be examined separately below.

5.1.1 Methodology and assumptions

Expenditure multiples for ASD

No publicly available data sources have been identified on the healthcare expenditures by or on behalf of people with ASD in Australia. However, there is clear evidence to suggest that on average, people with ASD do incur higher healthcare expenditures than people that don't have ASD.[139] In this regard, three US studies have been identified, all of which have sought to estimate the healthcare expenditures of children with ASD. All studies compare expenditures for children with ASD with expenditures for children without the condition. The studies are:

- Croen et al (2006), "A Comparison of Health Care Utilisation and Costs of Children with and without Autism Spectrum Disorders in a Large Group Model Health Plan".[140] The study compares expenditures on 3,053 children with ASD (aged between two and eighteen) with a random sample of 30,529 children without ASD, all of whom were enrolled in the same health plan. Data was obtained from the health plan's administrative databases.
- Liptak, Stuart and Auinger (2006), "Healthcare Utilisations and Expenditures for Children with Autism: Data from US National Samples".[141] This study examined three national surveys which capture data on health care utilisation and costs for children and adults in the US. They identified specific expenditures for children with ASD and compared these to 'general' expenditures, as well as expenditures for children with intellectual disability and depression.

[139] For example, refer: Birenbaum, A., Guyot, D & Cohen, H. (1990). Health Care Financing for Severe Developmental Disabilities, Washington, American Association on Mental Retardation, Monograph 14.

[140] Croen, L., Najjar, D., Ray, T., Lotspeich, L., & Bernal, P. (2006). A Comparison of Health Care Utilisation and Costs of Children with and without Autism Spectrum Disorders in a Large Group Model Health Plan. Pediatrics, 118(4).

[141] Liptak, G., Stuart, T., & Auinger, P. (2006). Healthcare Utilisations and Expenditures for Children with Autism: Data from US National Samples. Journal of Autism and Developmental Disorders, Vol.38.

- Mandell, Cao, Ittenbach and Pinto-Martin (2006), "Medicaid Expenditures for Children with Autism Spectrum Disorders: 1994 to 1999".[142] This paper examined Medicaid expenditures in one large county in Pennsylvania, comparing expenditures for 334 children with ASD with other Medicaid-eligible children (that did not have ASD), as well as 1,467 children with intellectual disability.

These studies contain data on:

- healthcare utilisation;
- average annual expenditures (by category); and
- the expenditure multiples for children with ASD compared to those without ASD (for example, the average annual expenditure on inpatient hospital services for a child with ASD was x times the expenditure on these services by children without ASD).

No distinction is made between children with autism and Asperger's in any of the studies.

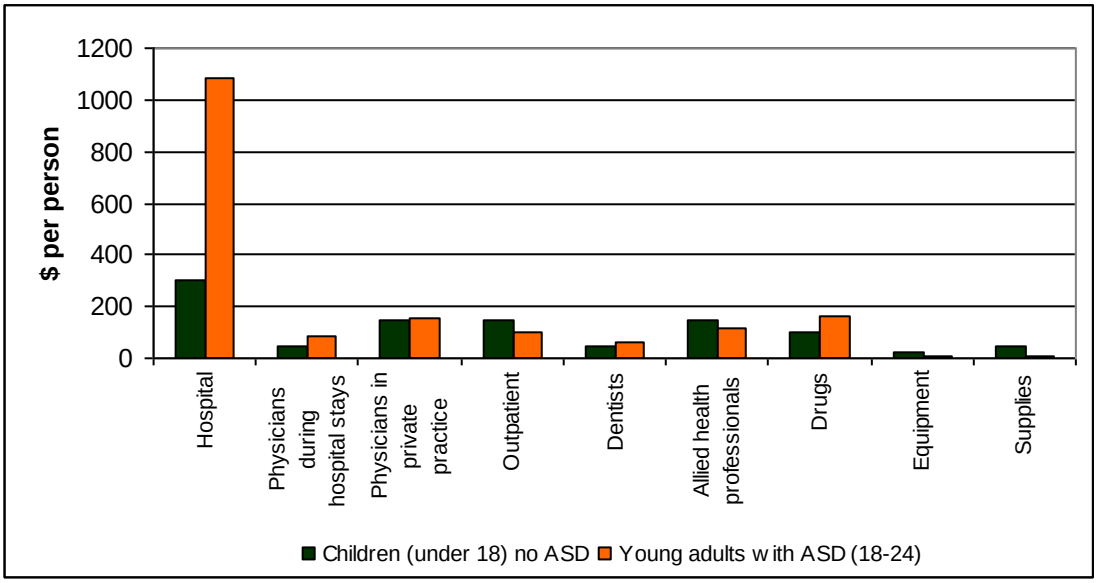
Given the differences between the US and Australian healthcare systems, it was not considered appropriate to take the actual cost estimates and convert them to Australian dollars. However, the expenditure multiples should be reasonably indicative of the incremental expenditure on healthcare services for children with ASD in Australia, although it is recognised that there may be some differences between the two jurisdictions.

Another issue that needs to be addressed here is the applicability of this data to expenditure by adults (as all of these studies relate to children with ASD). Analysis by Birenbaum, Guyot and Cohen (1990), reveals that average healthcare expenditures for young adults with ASD (aged between 18 and 24) was actually higher than average healthcare expenditures for children in most areas, particularly hospital services.[143] This is shown in Figure 1 (while the data itself is quite outdated, the relativities are likely to remain reliable).

[142] Mandell, D., Cao, J., Ittenbach, R. & Pinto-Martin, J. (2006). Medicaid Expenditures for Children with Autism Spectrum Disorders: 1994 to 1999. Journal of Autism and Developmental Disorders, 36(4).

[143] Birenbaum, A., Guyot, D & Cohen, H. (1990). Health Care Financing for Severe Developmental Disabilities, Washington, American Association on Mental Retardation, Monograph 14.

Figure 1 Average annual expenses for specific health services 1985/86: children and young adults (US$)



Data source: Birenbaum, A., Guyot, D & Cohen, H. (1990). Health Care Financing for Severe Developmental Disabilities, Washington, American Association on Mental Retardation, Monograph 14, pp.65-66.

While expenditures on healthcare services will vary during the course of a person's life, there is no evidence to suggest that the estimates provided for children cannot be applied to adults - in fact it is possible that this will underestimate the expenditure for adults. In the absence of more detailed data by age category, it has therefore been assumed that the expenditure multiples can be applied to all people with ASD.

Estimating expenditure per person

These multiples will then need to be applied to an estimate of average expenditure on health care per person in Australia (for people without ASD). No data could be found on the average expenditure on health for people without ASD (or any other conditions). However, the Australian Institute of Health and Welfare (AIHW) publishes total expenditure on healthcare for the total population, which can be converted to an average expenditure per person using relevant population statistics. The latest data available was for 2008-09,[144] so this was inflated to December 2010 dollars using the health care component of the CPI.[145]

The AIHW data breaks down expenditure into Government and non-Government expenditure on the following services:

[144] Australian Institute of Health & Welfare (2010). Health Expenditure Australia 2008-09, AIHW Cat.No. AWE 51, AIHW, Canberra.

[145] Australian Bureau of Statistics (2011), Consumer Price Index, December Quarter 2010, Cat. 6401.0.

- hospitals (public and private)
- high level residential care
- patient transport
- medical services
- other health practitioners
- medications
- aids and appliances
- other non-institutional services (includes community health, public health, dental and administration)
- research.

Where expenditure multiples could be obtained for ASD for a particular category, that multiple was applied to the average expenditure per person to produce an estimate of the average expenditure per person for ASD. If no multiple was available for that category (for example, there was nothing available for dental services), the incremental expenditure on that particular category was assumed to be zero. The increments applied are shown in Table 4.

Table 4 Healthcare expenditure multiples for ASD

AIHW Data Category	Multiple	Source
Hospitals - public	1.9	Croen et al ("inpatient hospital – non-psychiatric")
Hospitals - public psychiatric	12.4	Croen et al ("inpatient hospital – psychiatric")
Hospitals - private	1.9	Croen et al ("inpatient hospital – non-psychiatric")
High level residential care		Data not available
Ambulance and other	1.03	Mandell et al ("ambulatory")
Medical services	4.35	Liptak et al ("physician")
Other health practitioners	6.17	Liptak et al ("non-physician")
Medications	10.11	Average of Croen at al (7.6) and Liptak et al (12.61)
Aids and appliances		Data not available
Other non-institutional services		Data not available

The average expenditure per person with ASD represents the total expenditure, not the incremental expenditure. Hence, the average expenditure per person without ASD was subtracted from this total expenditure, to produce an estimated incremental

expenditure for each category. The prevalence assumptions are then applied to produce a total estimated annual expenditure for people with ASD.

5.1.2 Cost estimates

The relevant estimates for each cost category are provided in Table 5. As previously outlined, two overall estimates have been produced – a 'lower bound' based on the low prevalence estimate and an upper bound for the higher prevalence estimate. No distinction has been made between autism and Asperger's/HFA as the data was not available to do this.

Table 5 Healthcare cost estimates: ASD

AIHW Data Category	Average cost per person ($Dec 10)	Average cost per person with ASD ($Dec 10)	Incremental cost per person with ASD ($Dec 10)	Total cost ASD – low prevalence estimate ($'000 Dec 10)	Total cost ASD – high prevalence estimate ($'000 Dec 10)
Hospitals - public	1,567	2,977	1,410	117,271	198,631
Hospitals - private	392	744	353	29,313	49,650
Patient transport	112	115	3	279	473
Medical services	929	4,043	3,113	258,868	438,463
Other health practitioners	161	991	831	69,077	117,001
Medications	713	7,205	6,492	539,826	914,340
TOTAL	**3,874**	**16,076**	**12,202**	**1,014,636**	**1,718,557**

Note: Totals may not exact due to rounding.

This suggests that the total annual healthcare cost for people with ASD is between $1,015 million and $1,719 million.

5.1.3 Issues and limitations

There are a number of limitations to this analysis. The main one is that the increments for ASD should be applied to average expenditures for people that don't have ASD. No data could be found on this, nor was it possible to make adjustments to the AIHW data to 'remove' the impact of ASD and all other health conditions.

The per capita 'average expenditure' that has been estimated here, before applying the increments for ASD, would already include people with ASD and a range of other health conditions. This may therefore overstate the estimates of actual expenditure incurred by people with ASD (and contain an element of double-counting), notwithstanding that in the AIHW estimates, the higher healthcare expenditures of people with ASD and other conditions are 'averaged out' across the entire population.

Arbitrary adjustments can be made to test the sensitivity of the results to key assumptions. For example, the AIHW data could be reduced to some arbitrary amount that could be assumed to be the average healthcare expenditure by a 'healthy' Australian in a year. If this expenditure was 50% of the current total per capita amounts, this essentially halves the estimates as follows.

Table 6 Healthcare cost estimates: ASD – reduced baseline for average cost

AIHW Data Category	Average cost per person ($Dec 10)	Average cost per person with ASD ($Dec 10)	Incremental cost per person with ASD ($Dec 10)	Total cost ASD – low prevalence estimate ($'000 Dec 10)	Total cost ASD – high prevalence estimate ($'000 Dec 10)
Hospitals - public	784	1,489	705	58,636	99,315
Hospitals - private	196	372	176	14,657	24,825
Patient transport	56	58	2	140	237
Medical services	465	2,021	1,557	129,434	219,231
Other health practitioners	80	496	415	34,539	58,500
Medications	357	3,603	3,246	269,913	457,170
TOTAL	**1,937**	**8,038**	**6,101**	**507,319**	**859,278**

Note: Totals may not exact due to rounding.

It is likely that the AIHW data does not capture all expenditure on healthcare services by the Australian population. More importantly, it is possible that people with ASD utilise other healthcare services that have not been captured above, for example, alternative therapies, which is understood to be commonly used by people with ASD. It does also not capture costs such as travel to and from appointments.

Notwithstanding this, a conservative approach has been taken to the estimation of all costs in this study, which means ensuring that the probability that the costs are understated is higher than the probability that they are overstated.

To ensure this principle is maintained here, the estimates in Table 6 will be adopted. While the adjustments that have been made are entirely arbitrary, and potentially severe, there is no other robust way of adjusting the expenditures to ensure that the average expenditure per person does not include costs for ASD or other unrelated conditions. The alternative is to retain the unadjusted numbers, which risks double-counting at least some of the healthcare costs of ASD.

The other limitations of this analysis are:

- it does not capture differential service need within the population of people with ASD. This is likely to be highly variable, with some people having a high level of need and others relatively low needs. For example, the study by Barton and

Volkmar previously cited suggests that comorbid medical conditions (but not necessarily all medical conditions) are more likely in individuals with lower IQ[146];

- it does not capture any differences in service utilisation for people of different ages (for example, children, adults and older people); and
- the different health systems in the US and Australia may result in some differences in service use. Ideally, the expenditure multiples would be estimated using Australian data.

5.2 Social services

5.2.1 Use of social services by people with ASD

Social services could be utilised by people with ASD for a number of reasons. Services utilised include:

- residential accommodation, or services to support people living in their own homes;
- employment support (including assistance in finding employment or providing employment in a supported facility);
- community access services;
- respite for families; and
- personal care services, for people who need assistance with daily living. This could also extend to more regular use of services that are also used by people without ASD, such as cleaning and home maintenance.

Services are funded by the State and Commonwealth Governments under the Commonwealth State/Territory Disability Agreement (CSTDA), with the services themselves delivered by Government and non-Government organisations.

Consumers will need to meet certain criteria to receive these services, which will consider factors such as the individual's level of core activity restriction. In particular, the presence of a profound or severe core activity limitation means that an individual will sometimes or always need assistance with activities of self-care, mobility and communication.[147]

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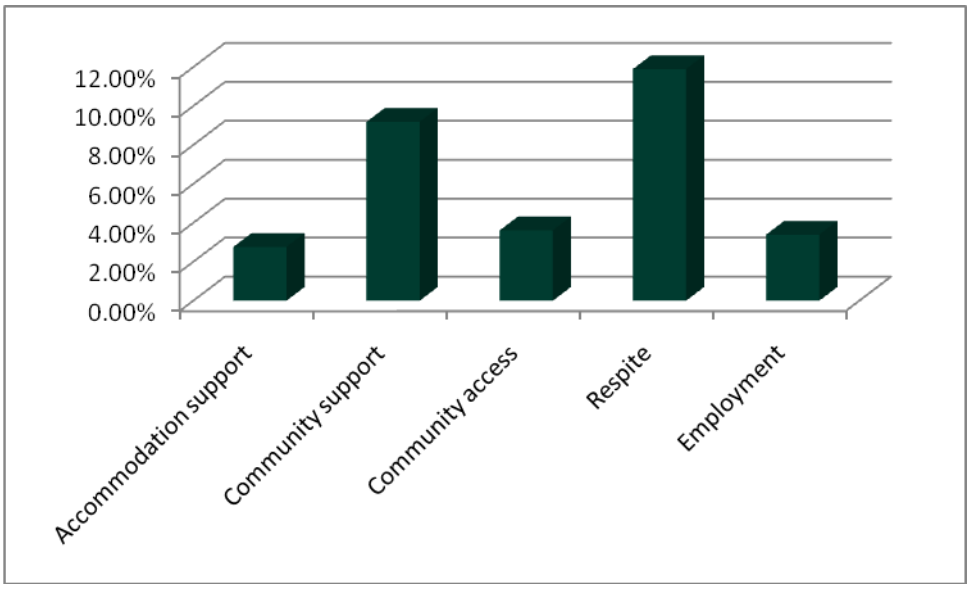
146 Barton, M. & Volkmar, F. (1998).

147 Australian Institute of Health and Welfare (2006). Disability and Disability Services in Australia, AIHW AIS Cat. No. DIS43, Australian Institute of Health and Welfare, Canberra, p.2.

In 2008-09 people with ASD comprised around 6.1% of the total number of CSTDA service users (it does not distinguish between different conditions on the autism spectrum).[148] The following chart shows the proportion of services used by people with ASD by service type, as a percentage of the number of total service users.

Figure 2 CSTDA Services: Service Users with ASD as a % of Total 2008-09



Data source: Australian Institute of Health and Welfare, Data Cube: Users of all CSTDA-funded Services, 2008-09, www.aihw.gov.au. {Accessed 6 April 2011.}

This shows that respite remains the dominant type of service used by people with ASD (compared to our previous report which was based on 2004-05 data), which is not surprising given the evidence previously discussed regarding the stress on carers that can arise as a result of caring for a child or adult with ASD. Community support services are also heavily utilised.

5.2.2 Methodology and assumptions

As noted above, the proportion of CSTDA service users with ASD can be identified from AIHW data. This can then be applied to the total annual expenditure on CSTDA services by Government to estimate the expenditure attributable to ASD.

As these services are only used by people with disabilities, it is unnecessary to apply an incremental approach here (in other words, the incremental use of services by people with ASD will be 100%). This is therefore applying a top-down approach. Given

[148] Australian Institute of Health and Welfare (2011). Disability Support Services 2008–09: National Data on Services Provided under the Commonwealth State/Territory Disability Agreement, AIHW Cat. No. DIS 58, Disability Series, Australian Institute of Health and Welfare, Canberra, p.25.

service users are likely to have a profound or severe core activity restriction, it is most likely that they have autism, rather than HFA or Asperger's. Hence, this CSTDA data is unlikely to capture any utilisation of services by people in these higher-functioning categories.

The latest expenditure data available is for 2008-09.[149] This has therefore been inflated by the CPI to produce estimates as at December 2010.

5.2.3 Cost estimates

The estimated costs are shown in the following table.

Table 7 Expenditure on CSTDA services for people with ASD: 2008-09

Service type	$'000 Dec 2010
Accommodation support	157,287
Community support	50,337
Community access	39,467
Respite services	21,732
Employment services	34,531
Advocacy, info & print disability	3,378
Other support services	9,433
TOTAL	**316,165**

Source: Australian Institute of Health and Welfare (2011), Disability Support Services 2008-09, Report on Services Provided under the Commonwealth State/Territory Disability Agreement and the National Disability Agreement, Canberra, January.

This shows that the total expenditure on services for people with ASD provided under the CSTDA is currently approximately $316 million per annum.

5.2.4 Issues and limitations

These estimates should be a reliable indicator of the costs of services provided under the CSTDA for people with ASD. In so doing, it only captures services provided under the CSTDA. It does not include the other services and supports that may be accessed and funded by people with ASD and their families. For example:

- people eligible for services may seek additional services that are funded out of their own pockets, for example, personal care, additional respite etc; and
- people that are not eligible for services under the CSTDA may still require assistance and hence access services from elsewhere. This could include people

[149] Australian Institute of Health and Welfare (2011).

with ASD with a less severe core activity restriction, including people with HFA and Asperger's.

It is not possible to estimate what the extent of this additional service use might be.

These estimates therefore only capture public expenditure on services for people with ASD. It does not include any private expenditure. These estimates should therefore be regarded as conservative.

5.3 Education expenditure

5.3.1 Utilisation of special education by people with ASD

Children with ASD will generally require some form of education support depending on their level of ability, ranging from a few hours help through to supervision from two carers in a residential setting.[150] Unlike the other expenditures examined so far, which can be incurred (in varying degrees) throughout the course of a person's life, this area will only relate to children with ASD.

Outcome studies have sought to measure the educational needs and attainment levels of the individuals in the sample groups and can be used to provide estimates of the number of children with ASD that may require special education services and how this varies across the spectrum of disorders.

A study by Howlin (2004) estimated that only 10 of the 68 individuals (14.7%) in the original sample group had been educated in a 'mainstream' school.[151] The remainder had attended various forms of specialised schooling such as special education schools, schools for individuals with learning disabilities, hospital schools or home schooling. Therefore, according to this data, over 80% of the individuals in this sample group utilised some form of special education.

The results from Howlin's study are also consistent with the results obtained from the study by Kobayashi, Murata and Yoshinaga (1992).[152] The results of the study demonstrate that, at the age of 12, approximately 70% of the sample group attended special education.

[150] Seltzer, M., Shattuck, P., Abbeduto, L., & Greenberg, J. (2004). p.16.

[151] Howlin, P., Goode, S., Hutton, J. & Rutter, M. (2004). Adult Outcome for Children with Autism. Journal of Child Psychology and Psychiatry, 45 (2).

[152] Kobayashi, R., Murata, T. & Yoshinaga, K. (1992).

A study by Mawhood, Howlin and Rutter (2000) compared the outcomes for a group of people with autism with those for a group of people with developmental language disorders.[153] Of the 19 adult males with autism, only two had attended mainstream school classes, implying that close to 90% had attended special education.

These studies demonstrate that a very high proportion of children with autism require special education services, with estimates ranging from 70 to 90%. However, these estimates are much lower for outcome studies for individuals with HFA. For instance, a study conducted in the late 1980s by Szatmari et al concluded that approximately 50% of the group of individuals with HFA required the use of special education resources.[154]

These results are supported by those found by Venter, Lord and Schopler (1992), which examined a group of 58 individuals with HFA. Of this sample group, the study found that only 28 (48.3%) attended special education.[155]

5.3.2 Methodology and assumptions

As there is no published data on expenditure on education for children with ASD in Australia, a bottom-up approach to estimating these costs will again be taken. The analysis has been limited to estimating the costs of special education. While it is likely that there are children with ASD in mainstream schools who will require additional services and supports, data on this is not readily available.

Estimation of the relevant costs of special education will require assumptions regarding:

- the proportion of children with ASD requiring special education
- the incremental cost of special education per child.

Proportion of children requiring special education

The studies cited above provide reasonable estimates concerning the utilisation of special education by children with ASDs. Upon examination of these results, two assumptions have been made, being that special education will be required for:

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[153] Mawhood, L., Howlin, P. & Rutter. M. (2000). Autism and Developmental Receptive Language Disorder – a Follow-Up Comparison in Early Adult Life. II: Social, Behavioural and Psychiatric Outcomes. Journal of Child Psychology and Psychiatry, 41 (5).

[154] Szatmari, P., Bartolucci, G., Bremner, R., Bond, S., & Rich, S. (1989). A Follow-Up Study of High-Functioning Autistic Children. Journal of Autism and Developmental Disorders, 19 (2).

[155] Venter, A., Lord, C. & Schopler, E. (1992). A Follow-Up Study of High Functioning Autistic Children. Journal of Child Psychology, 53 (3).

- 80% of children with conventional autism
- 50% of children with HFA/Asperger's.

Incremental cost of special education

A number of studies have been conducted on the costs of special education both for individuals with ASD and for those with other learning disabilities. These studies have produced a range of estimates on the costs of special education compared to the costs of standard education.

Jarbrink and Knapp estimated the costs of special education for individuals with ASD in the UK.[156] The study used data obtained from sample groups as well as unit costs derived from the Personal Social Services Research Unit (PSSRU) to estimate the average cost for children with ASD attending special schools between the ages of five and nineteen. After mainstream schooling costs had been subtracted, the study estimated the average annual cost of special education to be £10,778, or $42,105[157] in December 2010 Australian dollars.

The study also determined a greater degree of variability in relation to special school attendance for children with HFA. For these children, the study estimated an average annual cost of £7,216, or $28,190 in December 2010 Australian dollars.[158]

Jarbrink, Fombonne and Knapp conducted another survey in 2003 with the aim of using a diary schedule survey method to estimate the additional educational costs incurred by parents with children with ASD.[159] The mean educational cost estimated by the study was measured at £11,638, equating to $40,716[160] in December 2010 Australian dollars. These figures support those obtained in Jarbrink and Knapp's previous study.

Another study that can provide estimates concerning the differential value between the costs of special and standard education is the benefit-cost analysis of childhood intervention programs undertaken by Masse and Barnett (2002).[161] This study estimates

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156 Jarbrink, M., & Knapp, M. (2001). The Economic Impact of Autism in Britain. Autism, 5(1).

157 Total estimates were in 1997-98 GBP. It is therefore assumed that all costs cited in the report were measured on this basis. Converted to AUD at the then prevailing exchange rate and inflated to December 2010AUD.

158 Jarbrink, M., & Knapp, M. (2001).

159 Jarbrink, K., Fombonne, E. & Knapp, M. (2003). Measuring the Parental, Service and Cost Impacts of Children with Autistic Spectrum Disorder: A Pilot Study. Journal of Autism and Developmental Disorders, 33 (4).

160 All estimates were in 1999-2000 GBP. Converted to AUD at the then prevailing exchange rate and inflated to December 2010AUD.

161 Masse, L. & Barnett, W. (2002). A Benefit Cost Analysis of the Abecedarian Early Childhood Intervention, National Institute for Early Education Research, New Jersey.

the costs for standard and special education at $7,931 and $18,341 respectively (1999 US dollars). When converted to December 2010 Australian dollars, these figures translate to $17,107 and $39,561[162], demonstrating a cost differential of $22,454.

The 2010/11 Queensland State Budget provides cost estimates for the 2009/10 period for various activities, including standard and special education.[163] The Ministerial Portfolio Statement for the Department of Education and the Arts listed the cost of standard education at $11,026 per student. The average cost per student of special education services was listed at $26,152. These two figures provide an incremental difference of $15,127.

The Queensland data is considered appropriate to use and is assumed to be sufficiently representative of the average cost per child of special education services in Australia.[164] The incremental cost of special education is $15,127, or $15,135 in December 2010 dollars.

For individuals with HFA/Asperger's, a lower estimate will be applied as the special education services required have been shown to be less intensive than for children with conventional autism. Jarbrink and Knapp[165] estimated the special education costs for children with HFA to be approximately 67% of their estimated costs for children with autism. This assumption will be applied here. This will imply a special education cost for these children of $10,141 per child with HFA/Asperger's.

Calculation

Applying these assumptions, the total annual expenditure on special education per child was estimated using the following steps:

1. estimate the number of children of school age in the total population of people with ASD, which was done by applying the current proportion of the total Australian population that is aged between five and seventeen years[166];

[162] Converted to AUD at the then prevailing exchange rate and inflated to December 2010AUD.

[163] Queensland Government (2010). Service Delivery Statement (State Budget Paper 5), Department of Education and Training, p.3-83.

[164] A recent article cited an estimated cost of special education per child of $27,500 in New South Wales and $21,000 in Victoria. Refer: Patty, A. (2011). "Review Identifies $100m in Cuts for Special Needs", Sydney Morning Herald, 21 March, http://www.smh.com.au/national/education/review-identifies-cuts-of-100m-in-special-needs-20110320-1c2dl.html. {Accessed 7 April 2011.}

[165] Jarbrink, M., & Knapp, M. (2001).

[166] Australian Bureau of Statistics (2010). Population by Age and Sex: Australian States and Territories, June 2010, Cat. 3201.0.

2. estimate the number of children with autism and HFA/Asperger's that are assumed to require special education services; and

3. apply these numbers to the estimated incremental cost of special education per child, to produce an estimate of total annual expenditure on these services.

5.3.3 Cost estimates

The estimated costs of special education are provided in Table 8.

Table 8 Estimated annual costs of special education for children with ASD

Category	Total annual cost ($'000 Dec 2010)
Autism (excluding HFA) – low prevalence	80,947
Autism (excluding HFA) – high prevalence	157,880
HFA/Asperger's – low prevalence	35,017
HFA/Asperger's – high prevalence	50,611
Total – low prevalence	**115,964**
Total – high prevalence	**208,492**

This suggests a total annual cost of between $116 and $208 million.

5.3.4 Issues and limitations

The analysis assumes that the educational requirements of children with HFA are similar to children with Asperger's. While longer-term outcomes for people in each diagnostic category are seen to 'merge', there is no data to suggest that their educational needs will be the same. However, in the absence of any data on the possible cost differentials between these two categories, no distinction was made between these two conditions.

As noted previously, the outcomes studies generally reported data on the type of school attended (that is, special or mainstream school). However, it is possible that children that do not attend a special school still require additional services, resulting in higher costs that will not be captured here. Also, this does not capture additional private expenditures that might be incurred by families, such as tutoring.

The results will be very sensitive to the assumptions underpinning them. Sensitivity analysis has been undertaken on some of the key assumptions and the results are summarised in Table 9.

Table 9 Education cost estimates: sensitivity analysis

Scenario	Total annual cost ($'000 Dec 2010) - low prevalence	Total annual cost ($'000 Dec 2010) - high prevalence
Base case	115,964	208,492
More children with HFA/Asperger's require special education, eg 65%	126,469	223,675
Fewer children with HFA/Asperger's require special education, eg 35%	105,459	193,308
More children with autism require special education, eg 90%	126,083	228,227
Fewer children with autism require special education, eg 70%	105,846	188,757
Cost per child of special education for HFA/Asperger's is 90% of the cost for autism	127,985	225,866
Cost per child of special education for HFA/Asperger's is 50% of the cost for autism	107,079	195,650

The range of results produced here is between $105 and $228 million per annum.

5.4 Employment

5.4.1 Employment impacts for people with ASD

As noted previously, ASD can impact a person's ability to secure and retain employment, resulting in unemployment or underemployment. A summary of the findings emerging from outcomes studies include:

- Howlin et al (2004)[167]: involves 68 adults with autism with an IQ of at least 50. 23 of this group were in some form of employment, although 11 of these were in a sheltered work facility and one was in a voluntary/low-paid scheme. Excluding these 12, 18% of this group were employed in the workforce.
- Barnard et al (2001)[168]: the results of Barnard's survey of 438 adults suggested that only 2% of those at the lower functioning end of the spectrum were employed. 12% of those in the higher-functioning category were in full-time paid employment and another 6% were in part-time.
- Mawhood et al (2000)[169]: of the nineteen young adults with autism in this study, only one was in independent employment (5% employed).

[167] Howlin, P., Goode, S., Hutton, J. & Rutter, M. (2004).

[168] Barnard, J., Harvey, V., Potter, D., & Prior, A. (2001).

[169] Mawhood, L., Howlin, P. & Rutter. M. (2000).

- Szatmari et al (1989)[170]: this study included 16 adults with an IQ of at least 65. Six were employed full-time and one worked in a family business (44% employed). Three were studying.
- Venter et al (1989)[171]: 22 of the subjects in this group were over 18 at the time of this study, and six of these were "competitively" employed, including one university graduate (27% employed). All except this graduate were described as being in relatively low level jobs in service industries.
- Larsen & Mouridsen (1997)[172]: this group consisted of eighteen adults (all in their thirties at time of follow-up), half of whom had autism and half Asperger's. Three were employed (17% employed).
- Kobayashi et al (1992)[173]: 41 of 197 were employed and another two helped with the family business (21% employed). Six were studying.
- Jennes-Coussens et al (2006)[174]: 50% of this group of young men with Asperger's were employed, and another three were studying.
- Howlin (2003)[175]: this study compared 34 adults with HFA with 42 adults with Asperger's. 38% of the HFA group were in independent or sheltered employment, compared to 40% of the Asperger's group (note: the numbers quoted in the other studies do not include sheltered employment).

The results from these studies show that only between 2% and 18% of adults with autism were employed, and between 17% and 50% of those with HFA/Asperger's. It should be noted that in some studies, some of the subjects in that were not employed were studying.

5.4.2 Methodology and assumptions

The focus of the costing analysis will be on unemployment, as there is no data available regarding the nature and extent of underemployment (although a number of the studies suggested that many of those that were employed were in relatively low-skilled

170 Szatmari, P., Bartolucci, G., Bremner, R., Bond, S., & Rich, S. (1989).

171 Venter, A., Lord, C. & Schopler, E. (1992).

172 Larsen, F. & Mouridsen, S. (1997). The Outcome in Children with Childhood Autism and Asperger Syndrome Originally Diagnosed as Psychotic. A 30-year Follow-up Study of Subjects Hospitalised as Children. European Child and Adult Psychiatry, Vol.6, pp.181-190.

173 Kobayashi, R., Murata, T. & Yoshinaga, K. (1992).

174 Jennes-Coussens, M., Magill-Evans, J. & Koning, C. (2006).

175 Howlin, P. (2003).

jobs). While outcomes were highly variable overall, there is a clear difference between outcomes for individuals with autism and those with HFA/Asperger's, so a distinction will need to be drawn here. Further, given workforce participation rates and average weekly earnings vary between males and females, and males with ASD outnumber females by about 4:1 (on average), estimates have been developed by sex.

Valuing employment impacts

There are two main approaches to estimating the employment impacts of illness. The first is the human capital method. This seeks to measure the lost earnings and production for the economy as a result of an individual being unable to work. Assuming that earnings are an appropriate measure of the individual's contribution to production, the cost of this lost productivity is measured based on current wage rates.

This method relies on a number of key assumptions:[176]

- there is full employment and full productivity in the economy
- labour markets are competitive
- transaction costs are low
- the wage rates paid directly reflects the individual's contribution to production.

The second approach, the friction cost method, adopts the perspective of the firm. It assumes that if an individual is unable to work due to illness, the 'cost' is the cost to the firm in the short-term of covering this employee's absence and eventually replacing them. The 'friction period' is the period between the loss of the worker and eventual restoration of the lost production of that worker. All costs associated with this loss during the friction period are measured (e.g. any loss in production, as well as the costs of restoring the lost production). A key assumption here is that there is sufficient unemployment in the economy so that the worker can be replaced.

The human capital approach will be adopted here. In addition to it being the more commonly used approach, ASD is not a 'temporary illness' and hence if an individual is unable to work due to their condition, it is likely to have a more permanent impact on productivity. Further, the economy is currently close to full employment and it is therefore unrealistic to assume that there is an adequate pool of appropriately skilled labour to replace the number of people with ASD that may be unable to work.

[176] Tramner, J., Guerriere, D., Ungar, W., & Coyte, P. (2005). Valuing Patient and Caregiver Time: A Review of the Literature. Pharmacoeconomics, 23 (5), p.451.

As noted above, a key assumption of this approach is that the value of the individual's contribution is equal to the current wage rate (average weekly earnings). It is also assumed that if people with ASD were able to work, they would have the same participation rates, work the same average weekly hours, and earn the same wage rates as people without the condition.

To estimate the cost of lost productivity for people with ASD, the following steps were undertaken:

1. Estimate the number of people with ASD that are of working age (that is, between 15 and 65 years). This was based on total population statistics (that is, the proportion of the Australian population that was aged between 15 and 65 years based on the most recent ABS data).[177]

2. Estimate the number of people with ASD that would be eligible to work based on workforce participation rates sourced from the ABS (73% of the male population and 60% of females).[178] These numbers were broken down by:
   - sex
   - between autism and Asperger's/HFA.

3. The number of people employed in each group was then estimated. As noted above, the outcomes studies revealed highly variable results. The assumptions selected were:
   - the mid-point of the two studies for autism (10%)
   - the average of the studies for HFA/Asperger's (excluding Howlin (2003), as this included sheltered employment), which was 30%.

4. The value of the lost productivity is then calculated by applying the relevant average weekly earnings for males and females (the latest estimates from the ABS are as at November 2010[179]) to the number of people in each sub-group that are eligible to work but are assumed to be unemployed.

5.4.3 Cost estimates

The resulting cost estimates are provided in Table 10.

[177] Australian Bureau of Statistics (2010). Population by Age and Sex: Australian States and Territories, June 2010, Cat. 3201.0.

[178] Australian Bureau of Statistics (2011). Labour Force, Australia, December 2010, Cat.6202.0.

[179] Australian Bureau of Statistics (2010), Average Weekly Earnings, November 2010, Cat. 6302.0. Estimates are trend estimates, total earnings.

Table 10 Estimated annual cost of unemployment for people with ASD

Category	Total annual cost ('000 Dec 2010) - low prevalence	Total annual cost ('000 Dec 2010) - high prevalence
Autism (excluding HFA)	1,035,207	2,019,082
HFA & Asperger's	831,778	1,202,196
Total	**1,866,985**	**3,221,278**

This shows that the costs of lost productivity are particularly significant, ranging between $1,867 million and $3,221 million per annum.

5.4.4 Issues and limitations

As noted previously, the employment outcomes data is highly variable and the assumptions made here should be treated with caution. As for all of the issues that have been examined, a robust, long-term analysis of the outcomes for individuals with ASD in Australia is needed.

There are a number of limitations of the human capital approach, which are largely based around its assumptions. For example, it may not always be appropriate to assume that an individual's contribution to production is equivalent to the wage rate, or that if a person was employed, the productivity of the economy would increase by the full amount of the contribution of that individual. Further, the application of average weekly earnings masks the significant variation in earnings across the labour force.

Other limitations include:

- the costs of underemployment have not been included, which would be difficult to estimate due to lack of data; and
- apart from the reduction in productivity, there are other social costs associated with unemployment that have not been included here. These costs can be significant and are considered in more detail in Appendix B.

The results will be very sensitive to the assumptions underpinning them. In particular, the key assumption here is the number of people with ASD that remain unemployed. Sensitivity analysis has been undertaken on this assumption and the results are summarised in Table 11.

Table 11 Employment cost estimates: sensitivity analysis

Scenario	Total annual cost ($'000 Dec 2006) - low prevalence	Total annual cost ($'000 Dec 2006) - high prevalence
Base case	1,866,985	3,221,278
Employment outcomes are higher than 10% for people with autism (e.g. 30%)	1,636,939	2,772,593
Employment outcomes are higher than 30% for people with HFA/Asperger's (e.g. 50%)	1,629,334	2,877,793
Employment outcomes are higher for both people with autism and HFA/Asperger's (e.g. 30% and 50% respectively)	1,399,288	2,429,108
Employment outcomes are lower than 10% for people with autism (e.g. 5%)	1,924,497	3,333,449
Employment outcomes are lower than 30% for people with HFA/Asperger's (e.g. 20%)	1,985,810	3,393,020
Employment outcomes are lower for both people with autism and HFA/Asperger's (e.g. 5% and 20% respectively)	2,043,322	3,505,191

The range of estimates here is from $1.4 billion to $3.5 billion.

5.5 Informal care

As noted above, caring for a child or adult with ASD can have a number of impacts on families. However, there is currently inadequate data to estimate some of these impacts, such as the impact of family stress or an increase in physical and/or mental health problems.

This analysis will therefore focus on the direct cost to the carer, which is referred to as the cost of informal care. This has been examined in a number of studies, including a comprehensive review undertaken by Access Economics.[180]

5.5.1 The value of informal care

Approaches used to value informal care

The wide range of literature on this topic provides a number of different options in terms of methodologies for estimating a value for informal care. The key methodologies applied are:

- opportunity cost method

[180] Access Economics (2010), The Economic Value of Informal Care in 2010.

- market cost (replacement cost) approach
- contingent valuation methods.

The two most commonly used methods for valuing informal care are the opportunity cost method and the market cost approach. The opportunity cost method measures the wages or benefits that are foregone by the caregiver as a result of their provision of informal care.[181] The opportunity cost of informal care is generally approximated by the market wage in the economy.[182] In addition to this, it is necessary to estimate the value of the leisure time that is foregone by the caregiver as this represents an additional opportunity cost that is not captured by lost earnings alone.[183]

The opportunity cost method has been criticised by many on the basis that it undervalues the caregiver's contribution and thus the value of informal care. The opportunity cost method has also received criticism on the basis that, despite being theoretically appealing, the method's practical application can pose serious problems due to the difficulties associated with attaching monetary values to things such as leisure time.[184]

Whilst the opportunity cost approach is essentially a valuation of the input, the market cost approach attempts to value the output of informal care by applying the market wage of a caregiver in the formal sector to informal care. Whilst this method is widely used in economic valuations, it does carry the weakness of potentially undervaluing the inputs that are sacrificed by the informal caregivers.[185]

Another possible method, and one that has increased in popularity in recent years, is the contingent valuation method (CVM). This approach to valuation involves asking caregivers to assess their willingness to pay (WTP) for not having to perform an additional hour of care.[186] An alternative is attempting to obtain an estimate of caregivers' willingness to accept (WTA) by asking caregivers what compensation they would require in order to provide an additional hour of informal care.[187]

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181 Arno, P., Levine, C. & Memmott, M. (1999). The Economic Value of Informal Caregiving. Health Affairs, 18 (2).

182 van den Berg, B., Brouwer, W. & Koopmanschap, M. (2004). Economic Valuation of Informal Care: An Overview of Methods and Applications. European Journal of Health Economics, 5(36).

183 Andersson, A. et al. (2004). Costs of Informal Care for Patients in Advanced Home Care: A Population-based Study. International Journal of Technology Assessment in Health Care, 19(4).

184 Brouwer, W. et al. (1999). The Valuation of Informal Care in Economic Appraisal. International Journal of Technology Assessment in Health Care, 15(1).

185 Brouwer, W. et al. (1999).

186 Brouwer, W. et al. (1999).

187 Brouwer, W. et al. (1999).

Despite having the advantage of being able to measure the caregiver's well-being, these contingent valuation methods have been criticised over their lack of accuracy. For instance, a caregiver's preferences may be made with regard for the well-being of others, not only their own. Also, monetary concerns tend to be relatively low in terms of the priorities of many informal caregivers. A major concern from the perspective of an economic valuation is that WTA and WTP measures are based on hypothetical rather than actual choice situations, thus reflecting revealed rather than stated preferences.[188]

Van den Berg and Ferrer-I-Carbonell (2007) expand on these ideas in their recent paper by focusing on obtaining a monetary estimation of the level of income required to maintain the caregiver's level of well-being after providing an additional hour of informal care.[189] This approach holds two important advantages over the other CV methods. First, it avoids the problem of results containing bias due to strategic behaviour by survey respondents. Second, a well-being valuation is derived from an individual's experienced utility rather than being based on hypothetical responses.

Estimates for the value of informal care

In their study on the economic value of informal care, Arno et al (1999) examined US data from national data sets such as the Survey on Income and Program Participation and the 1996 National Family Caregiving Survey to produce estimates for the number of caregivers in the US, the number of hours of care tasks performed each week and the overall cost of these activities.[190]

The analysis produced a prevalence estimate of 27.6 million caregivers in the US in 1997. Various surveys and studies that were analysed produced estimates of the overall number of care hours per week from between 22 and 70 hours per week. The study employed a market wage approach to value informal care with two possible wage rates considered: the minimum wage of $5.15 per hour and the average national wage rate for home health aides of $11.20 per hour. The study chose $8.18 (1997 USD) as a mid-range wage rate for valuation on the basis that informal care tasks contained wide variations in terms of skill level. The total value of informal care in the US in 1997 was estimated to be $196 billion.

188 van den Berg, B., Brouwer, W. & Koopmanschap, M. (2004).

189 van den Berg, B. & Ferrer-I-Carbonell, A. (2007). Monetary Valuation of Informal Care: the Well-being Valuation Method. Health Economics, 10.

190 Arno, P., Levine, C. & Memmott, M (1999).

As noted above, the recent study by van den Berg and Ferrer-I-Carbonell used the well-being valuation method to estimate the economic value of informal care.[191] The results obtained from the sample group exhibited average hours of informal care of 49 per week. At this average level of care, service responses indicated that caregivers would require 2.5% of their income as compensation in order to maintain a constant state of well-being after providing an additional hour of informal care. This equates to approximately 9.3 euros per hour, or $25.67 in December 2010 Australian dollars. It should be noted that the value of each hour of informal care increased as the number of hours provided decreased. For instance, for a caregiver providing 29 hours of care per week, an additional hour of care would be worth 16 euros ($44.18 December 2010 AUD).

In 2010, Access Economics published an updated study analysing the economic value of informal care in Australia.[192] The study estimated that approximately 129,900 carers would be unemployed as a result of informal care responsibilities in 2010 (1.1% of the country's workforce). Using the opportunity cost as its lower bound estimate, the study applied the average national wage rate of $968.10 per week to informal care. This method provided an economic value of informal care of $6.5 billion.[193]

In order to obtain an upper bound estimate for informal care, the study attached the wage rate of full-time carers and aides in the formal sector of the economy to the value of an hour of informal care. In August 2008 this wage rate was equal to $22.30, which increased to $31.04 when loading costs were added. Using this data, the replacement cost method yielded a value of $40.9 billion for informal care in Australia.[194]

Although the differential between these two estimates seems to be unreasonably large, it is important to note the fundamental differences between the two types of methodologies that are used. The opportunity cost method attempts to measure the resources that are diverted away from production as a result of informal care activities whilst the replacement cost method measures the resources that would need to be diverted from production in order to replace informal caregivers.[195]

Estimates of the hourly rate for informal care can be deduced by assuming that on average, 50 hours per week of informal care is provided by each caregiver. The Access Economics study effectively uses two different hourly rates – one for the opportunity

[191] van den Berg, B. & Ferrer-I-Carbonell, A. (2007).

[192] Access Economics. (2010).

[193] This comprises earnings foregone for primary carers of $4.6 billion and $1.9 billion for non-primary carers.

[194] Access Economics. (2010).

[195] Access Economics. (2010).

cost method and the other for the market cost approach. These two wage rates are $19.36 and $31.04 respectively, and provide a midpoint wage rate of $25.20/hour.

Incremental hours of care

The figures regarding weekly hours of informal care per week and the estimate of the value of an hour of informal care suggests that there is a substantial cost associated with informal care. This is further confirmed by the cost estimates obtained in the Access Economics study, with the replacement cost method yielding a national annual cost in excess of $40 billion.

However, caution must be exercised when seeking to determine the incremental cost of care, particularly for children. Many parents may already spend up to 50 hours per week caring for children without ASD, particularly for younger children. At least in terms of hours spent providing care, the 50 hours of care that might be spent by a parent caring for a child with ASD is therefore not necessarily incremental. It is possible that on average, more hours are spent providing care and/or the 'intensity' of that caring role is greater given the likely additional demands that are faced. However, there is no data available to reliably estimate this incremental effort.

This is not meant to imply that carers of children with ASD are not incurring additional costs. The difficulty here is that there is currently insufficient reliable data to estimate what this incremental effort might be.

However, the cost is far more likely to be incremental for an adult with autism who requires informal care. Therefore, it is suggested that most of the incremental costs of autism that can be attributed to informal care comes from caring for adults with ASD who are living at home and require assistance to complete basic tasks (that is, have very limited living independence). In order to gain a reasonable estimate of the reliance on informal care by adults with ASD, it is important to examine outcomes studies that have included a measure for living independence.

The outcome study by Howlin et al (2004) determined that 26 of the individuals (38%) lived at home with their parents, although some of them had a reasonable degree of living independence.[196] This finding is consistent with the study conducted by Szatmari et al (1989) which included a sample of 16 adults with HFA. The sample group had an average age of 26 years at the time of the follow-up, with 6 of (38%) requiring minimal supervision from other adults.[197]

[196] Howlin, P., Goode, S., Hutton, J. & Rutter, M. (2004).

[197] Szatmari, P., Bartolucci, G., Bremner, R., Bond, S., & Rich, S. (1989).

The study by Barnard et al (2001) revealed that approximately 50% of the individuals in the sample group were living at home with their parents.[198] It was also determined that 31% of adults that were living at home were being cared for on an informal basis by family members with 45% of these individuals requiring intensive care.

Gillberg (1991) made some conclusions that were derived from the results of previous outcome studies for people with ASD.[199] Included in these conclusions was an estimate of the proportion of adults with autism that required informal care. Gillberg estimated that some 60% of children with typical autism would grow up to be completely dependent on adults in all aspects of life.

Eaves and Ho (2008) found that 56% of the cohort of young adults they studied was living with their parents, with 35% in supported living arrangements.[200] In Saldana's study (2009), 87% were living with their parents and only 16% were not receiving support services.[201] 82.6% of the older youth and young adults in Liptak's study (2011) were living at home.[202]

Data from the AIHW revealed that in 2008-09, 39% of CSTDA service users (who are more likely to have a severe or profound core activity restriction) have an informal carer.[203] Just over one-third of these were aged less than 15 years and more than a third were aged between 25 and 44 years.

The AIHW also reported the frequency of service need by CSTDA service users. The following figure summarises the frequency of support needs in key life areas for all users of CSTDA-funded services in 2007-08.

198 Barnard, J., Harvey, V., Potter, D., & Prior, A. (2001).

199 Gillberg, C. (1991). Outcome in Autism and Autistic-like Conditions. Journal of the American Academy of Child and Adolescent Psychiatry, 30(3).

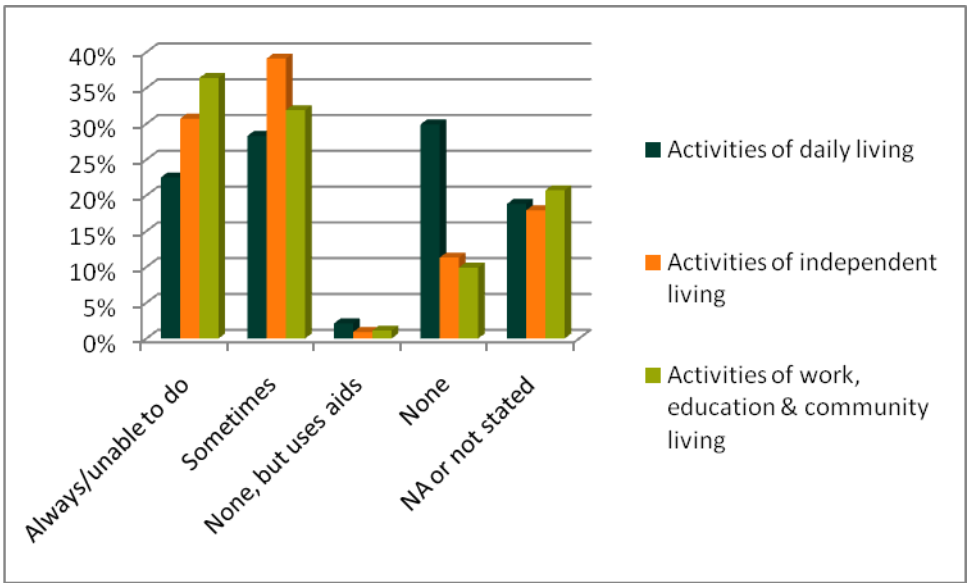
200 Eaves, L. & Ho, H. (2008).

201 Saldana, D., et al (2009).

202 Liptak, G., Kennedy, J. & Dosa, N. (2011).

203 Australian Institute of Health and Welfare (2011). p.32.

Figure 3 Users of CSTDA-funded services: Life area by need for support 2007-08



Data source: Australian Institute of Health and Welfare (2009). Disability Support Services 2007-08, National Data on the Services Provided under the Commonwealth State/Territory Disability Agreement, December, p.41.

This shows that nearly 50% of CSTDA service users require help with daily living (that is, self-care, mobility and communication) and nearly 70% need help with independent living (interpersonal interactions, learning and domestic life). Over 65% need help with work, education and community living.

In terms of the opportunity cost of care, the pilot study by Jarbrink, Fombonne and Knapp (2003) on the parental, service and cost impacts for children with ASD surveyed parents on the time they would spend on other activities if it were not for their parenting responsibilities.[204] The average time reported was 40 hours per week, which includes both work and leisure time.

5.5.2 Methodology and assumptions

As noted above, given uncertainties surrounding the incremental costs of caring for children with ASD (although it is not disputed that such costs may well be higher, particularly in terms of the intensity that is likely to be required to be applied in the caring role), the estimates of the costs of informal care has been limited to adults.

Given there is particular uncertainty surrounding the valuation of informal care and very limited data on its utilisation by people with ASD, two different methods have been applied: the replacement value and opportunity cost methods. In terms of the latter, two different sets of assumptions will be applied, one based on assumptions

[204] Jarbrink, K., Fombonne, E. & Knapp, M. (2003).

may by Jarbrink, Fombonne and Knapp[205], and the other by Ganz[206]. Again, it is assumed that the need for care, including hours per week required, will vary between adults with autism and adults with HFA/Asperger's.

Assumptions

Overall, the following assumptions have been made:

1. The number of adults with ASD was estimated by applying the current proportion of the Australian population aged over 19 years[207] to the estimated population of people with ASD.

2. It is estimated that 78.5% of carers are female[208]: this will have implications for the value of care provided based on relevant wage rates. It is also assumed that 14% of families with children are single parent families.[209]

3. It is extremely difficult to estimate the proportion of people with ASD needing care. As noted above, a number of the outcomes studies reported adults still living at home, however this does not always imply that they needed care. Reported outcomes are extremely variable. The assumptions that have been made are:
   - a lower bound of 16% needing care, which has been applied to people with HFA/Asperger's. This is from a study by Barnard et al (2001), which revealed that 50% of a large sample of people with ASD were living at home, with 31% of these being cared for by a family member;
   - an upper bound of 60%, which is based on the paper by Gillberg (1991), which estimated that 60% of children with 'typical' autism would grow up to be completely dependent on adults in all aspects of life. This has been applied to the estimated population of adults with autism.

4. The hours of care provided per week is also extremely difficult to estimate and are highly variable. Jarbrink et al (2003)[210] estimated between 40 and 60 hours however in some cases it is considerably lower and in others higher.

5. Foregone earnings have been valued at the same wage rates that were applied to value employment impacts.

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205 Jarbrink, K., Fombonne, E. & Knapp, M. (2003).

206 Ganz, M. (2006).

207 Australian Bureau of Statistics (2010). Australian Demographic Statistics June 2010, Catalogue 3101.0.

208 Australian Institute of Health and Welfare (2011).

209 Australian Bureau of Statistics (2008). Family Characteristics and Transitions, Australia, 2006-07, Catalogue 4442.0.

210 Jarbrink, K., Fombonne, E. & Knapp, M. (2003).

6. The replacement value for services has been valued at $31.04 per hour (Access Economics (2010)).

Replacement method

The replacement method estimates the number of hours of care provided per week and applies the market value of these services to calculate the total value of services. In terms of the hours of care provided per week, the mid-point of Jarbrink and Knapp's estimated range has been taken for an adult with autism (50 hours per week). There is no data to estimate the difference in the hours of care required for someone with HFA/Asperger's, so an arbitrary adjustment of 50% has been made (25 hours per week).

This data is then applied to the number of people with autism and Asperger's/HFA that are assumed to require care, as specified above. The hours of care are then valued at the assumed rate of $31.04 per hour.

Opportunity cost method: Jarbrink, Fombonne & Knapp assumptions

As noted above, this study reported that on average, parents with caring responsibilities would spend 40 hours per week in other activities (both work and leisure) if they did not have their caring responsibilities. For those people with ASD assumed to be needing care (based on the assumptions outlined above), this 40 hours per week is valued at the current wage rate, assuming that 78.5% of carers are female.

Opportunity cost method: Ganz assumptions

The study by Ganz (2006)[211], which estimated the costs of ASD in the US, valued the opportunity cost of unemployment of the carer. It assumes that:

- for HFA, fathers are unemployed 10% of the time and mothers 50% of the time
- for autism, fathers are unemployed 20% of the time and mothers 60%.

Ganz assumed no single parent families. For this study, it has been assumed that 14% of carer families are single parents (based on ABS data), and that they will be unemployed for the entire time. The relevant wage rates were applied for mothers and fathers, with the average wage rate for males and females applied to single parent families. Again, these valuations were only applied to the proportion of the population of adults with ASD that were assumed to be in need of care.

[211] Ganz, M. (2006).

5.5.3 Cost estimates

The costs estimated under each methodology are summarised in Table 12.

Table 12 Estimated annual costs of informal care for adults with ASD

Method	Total annual cost ($'000 Dec 2010) - low prevalence	Total annual cost ($'000 Dec 2010) - high prevalence
Replacement method	1,668,869	3,155,750
Opportunity cost – Jarbrink, Knapp & Fombonne assumptions	1,506,219	2,777,492
Opportunity cost – Ganz assumptions	1,175,061	2,183,808
Average	**1,450,050**	**2,705,683**

As expected, the replacement method produces the higher valuation. The average estimate across the three methods is between $1,450 million and $2,706 million.

5.5.4 Issues and limitations

There is significant variability between these methods. There are also limitations associated with each method and the assumptions that have been applied in developing the estimates. For example, the current wage rate is not necessarily an appropriate value of the opportunity cost of time spent in care activities, including the value of leisure time.

In particular, more reliable data is needed on the informal care provided for people with ASD, including the amount of time spent in caring activities for adults and children. This includes understanding the different care requirements for a person with autism versus HFA and Asperger's. As with all of these estimates, there will be considerable variability between the care needs for individuals across the autism spectrum, which is masked by the assumption of an average care requirement for each category.

The assumptions underpinning the demand for informal care will be particularly sensitive. This includes:

- the proportion of people who receive informal care
- the hours per week spent in informal care.

The sensitivity of the results to these assumptions is shown in the following table.

Table 13 Informal care cost estimates: sensitivity analysis (average costs across the three methods)

Scenario	Total annual cost ($'000 Dec 2010) - low prevalence	Total annual cost ($'000 Dec 2010) - high prevalence
Base case	1,450,050	2,705,683
Fewer average hours of help per week are needed (decreased from 50 to 40 hours per week for autism, and 25 to 15 hours for HFA/Asperger's)	1,325,694	2,476,369
More average hours of help per week are needed (increased from 50 to 60 hours per week for autism, and 25 to 35 hours for HFA/Asperger's)	1,574,406	2,934,998
Fewer average hours of help per week are needed for autism only (decreased from 50 to 40 hours)	1,351,890	2,514,231
More average hours of help per week are needed for HFA/Asperger's only (increased from 25 to 40)	1,489,344	2,762,477
Fewer people with autism and HFA/Asperger's need help (decreased from 60% to 30% for autism, and from 16% to 8% for HFA/Asperger's)	728,937	1,358,496
More people with autism and HFA/Asperger's need help (increased from 60% to 70% for autism, and from 16% to 25% for HFA/Asperger's)	1,799,965	3,313,073
Fewer people with autism only need help (decreased from 60% to 40%)	1,047,554	1,920,650
More people with Asperger's/HFA need care (increased from 16% to 30%)	1,676,962	3,033,648
Overall intensity of care required for both groups is higher (increased from 50 to 60 hours per week for autism for 70% of people with autism, and 25 to 35 hours for HFA/Asperger's, for 25% of people with HFA/Asperger's)	1,956,736	3,597,502
Overall intensity of care required for both groups is lower (decreased from 50 hours to 40 hours per week for autism for 40% of people with autism, and 25 to 15 hours for HFA/Asperger's, for 10% of people with HFA/Asperger's)	879,143	1,644,187

The lowest estimate here is $729 million per annum, and the highest is $3,598 million. As could be reasonably expected, the results were particularly sensitive to the assumption regarding the number of people requiring care.

5.6 Quality of life: the Burden of Disease

5.6.1 Valuing quality of life impacts

A condition such as ASD will adversely the quality of life for most if not all people with the condition, although again to varying degrees. This impact is termed the 'Burden of Disease' (BOD). Such an impact is not tangible, however, attempts are still made to measure this impact as part of cost of illness studies. Clearly, this will be controversial, given the difficulties in what is essentially placing a value on a healthy life. Nonetheless, this information is used by policy makers in allocating resources between different conditions.

DALYs

The World Health Organisation has developed a methodology to assess the BOD, as part of a global study. A key metric emerging from this is the Disability Adjusted Life Year (DALY), which is:[212]

> …a summary measure of population health that combines years of life lost from premature death and years of life lived in less than full health…

The objective of this measure is:[213]

- to allow estimates of health impact to be mapped to causes, whether in terms of disease and injury, or risk factors and broader social determinants;
- to provide a common metric for estimating population health impact and cost-effectiveness of interventions;
- to use common values and health standards for all regions of the world; and
- to provide a common metric for fatal and non-fatal health outcomes.

There are two dimensions to the DALY:

- the years of life lost due to premature mortality (YLL); and
- the equivalent years of healthy life lost due to the illness or disability, or morbidity (YLD).

[212] Mathers, C., Lopez, A., & Murray, C. (2006). The Burden of Disease and Mortality by Condition: Data, Methods and Results for 2001, World Health Organisation.

[213] Mathers, C., Vos, T. & Stevenson, C. (1999). The Burden of Disease and Injury in Australia, Australian Institute of Health and Welfare, Canberra, p.2.

As DALYs are measured in years, attempts have been made to value a year of healthy life; this value is then applied to the DALY in order to calculate the BOD for a particular condition.

Valuing a year of healthy life

The most common method for estimating the value of life is to obtain a measure of what people are willing to pay (WTP) for health. This means estimating how much people are WTP for a small increase in the probability of survival.[214] WTP estimates are typically gained by conducting a direct survey or some other preference method, which in turn enables economic researchers to obtain an estimate for the Value of a Statistical Life (VOSL).

In an analysis of 67 studies by Miller (1990), the methodology of each study fell into one of four categories.[215] These were:

- wage-risk studies: analyse compensating wage differentials associated with risky jobs;
- market studies: analyse the market for products that affect health and safety;
- behavioural studies: examine risk avoidance behaviour; and
- CV Surveys: measure how much people are WTP for a small change in risk.

In terms of the implementation of the VOSL measure (also referred to as VSL) in economic studies, it is important to recognise that the estimate that is obtained from a sample is largely dependent on the characteristics and preferences of that particular sample. Therefore, caution must be taken in universally applying the results that are derived from one VOSL study.[216]

Once a VOSL estimate has been obtained via one of the methods outlined above, it is possible to derive the Value of a Life Year (VOLY). This is taken to be a constant annual sum which carries a discounted value that is equal to the VOSL. This value represents an important measure for use in economic studies.[217]

The VOLY is estimated through the equation:

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214 Abelson, P. (2003). The Value of Life and Health for Public Policy. The Economic Record, 79.

215 Miller, T. (1990). The Plausible Range for the Value of Life – Red Herrings Among the Mackerel. Journal of Forensic Economics, 3 (3).

216 Viscusi, W. & Aldy, J. (2003). The Value of a Statistical Life: A Critical Review of Market Estimates Throughout the World. The Journal of Risk and Uncertainty, 27(1).

217 Abelson, P. (2003).

$$VOLY = VOSL/A \qquad \text{[Equation 1]}$$

where:

$A = [1-(1+r)-n]/r$

n = expected years of life remaining

r = discount rate.

It is important to note that the VOLY that is obtained from the estimated VOSL is highly sensitive to the discount rate that is used in this equation.[218]

Estimates for VOSL and VOLY

The following table provides the VOSL estimates obtained by a number of studies from around the world.

Table 14 VOSL estimates

Author/s	Year	Methodology	Country	VOSL Estimate
Mrozek & Taylor	2001	40 wage-risk studies	USA	$2 million
Krupnick, et al.	2000	CV Study	Canada	$0.5-$2 million
Guria, et al.	1999	CV Study	NZ	$2.1 million
Day	1999	16 wage-risk studies	USA/Can	$5.6 million
Desvouges, et al.	1999	28 wage-risk studies	USA	$3.6 million
Kneisner & Leith	1991	Wage-risk study	Australia	$2.2 million

Source: P. Abelson (2003). The Value of Life and Health for Public Policy. The Economic Record, 79.

Miller (1990) conducted a statistical analysis of 67 previous studies that had estimated the value of life.[219] The results of these studies yielded a wide range of estimates with the reported value of life ranging from $50,000 to $15 million, in 1988 prices.

In an attempt to narrow this range, the paper searched for biases within the studies. These biases include large variations in the age and incomes of the sample population as well as inaccuracies in terms of individuals' perceptions of risk. A statistical analysis revealed that 70% of the original 67 studies were fundamentally sound, yielding mean and median VOSL estimates of $2.2 million.[220]

An analysis of 20 wage-risk studies undertaken in the United States by Viscusi and Aldy (2003) revealed a range of VOSL estimates between $5 million and $12 million

[218] Abelson, P. (2003).

[219] Miller, T. (1990).

[220] Miller, T. (1990).

with a mean of approximately $7 million.[221] The first economic study outside of the United States aimed at estimating the value of life was undertaken in the United Kingdom by Marin and Psacharopoulos in 1982. This study estimated VOSL at $3.5 million whilst subsequent UK studies have produced some extremely large estimates, some upwards of $18 million. Estimates obtained by Canadian studies are more in line with US estimates, ranging between $3 million and $6 million in US dollars.

Once an appropriate value for the VOSL has been obtained, it is necessary to convert it to an annual value for the VOLY by using Equation 1. For example, if an estimated VOSL of $2 million is used and a discount rate of 5% is assumed, an individual with 40 healthy life years remaining has a VOLY of $116,556. However, if a discount rate of 1.5% is used, this estimate falls considerably to $66,854.

Australian Estimates

The single Australian study that was analysed in the 2003 paper by Abelson estimates a VOSL of $2.2 million in 2000 prices using a wage-risk study approach. The most reliable overseas studies yield estimates between $3.3 million and $6.6 million in AUD. Due to the similarities that exist between the Australian and European economies, Abelson suggests a conservative figure of $2.5 million be used as a VOSL for Australia.[222]

Allowing for 40 years of healthy life remaining and a discount rate of 3% (which is a commonly used proxy for the social discount rate), a VOSL of $2.5 million produces an estimated VOLY of $108,000. After adjusting for inflation, this value equates to approximately $130,000 in 2006 dollars. This value was used in our previous study. An updated paper by Abelson recommended that public agencies adopt a VOSL of $3.5 million and a VOLY of $151,000 (all estimates are in 2007 dollars).[223]

In 2008 Access Economics produced a report for the Office of the Australian Safety and Compensation Council, entitled *The Health of Nations: The Value of a Statistical Life*.[224] The report estimated a VOSL of $6 million (recommending sensitivity analysis at $3.7 million and $8.1 million). Assuming a discount rate of 3% and a 40 year remaining life expectancy, the recommended estimate for VOLY was $252,014 ($155,409 to $340,219). All estimates are in 2006 dollars. We have used the mid-point estimate as our

[221] Viscusi, W. & Aldy, J. (2003).

[222] Abelson, P. (2003).

[223] Abelson, P (2008). Establishing a Monetary Value for Lives Saved: Issues and Controversies, Working Papers in Cost-Benefit Analysis, Office of Best Practice Regulation, Department of Finance and Deregulation.

[224] Access Economics (2008). The Health of Nations: The Value of a Statistical Life, Report prepared for the Office of the Australian Safety and Compensation Council, January.

assumption for VOLY, inflated to December 2010 dollars. This amount is $281,996.Methodology and assumptions

The two key inputs required in calculating the BOD are therefore DALYs and the assumed VOLY. DALYs have been published by the AIHW for ASD.[225] Their most recent published estimates were for the year 2003, which reported DALYs for autism of 13,866. This comprises:

- 110 years of life lost due to premature mortality (YLL)
- 13,576 years of healthy life lost due to disability (YLD).

At the time we prepared our previous report, the latest available estimates (also from the AIHW) were for 1996, where the total DALYs for ASD were 5,897 years (these were the first such estimates that had been prepared). As there were no reported deaths due to ASD in that year, this estimate measures the morbidity burden (YLD) only, not mortality.

The more recent estimates are over double the 1996 figures. This should not be interpreted as suggesting that the DALYs for ASD have increased over time. This revised report sought to update and extend the original study. In so doing, enhancements to the methodologies used to estimate DALYs for different disabilities were made and better quality data was able to be accessed. Direct comparisons cannot therefore be made with the previous estimates. However, what we can say is that the recent estimates are likely to be more reflective of the DALYs for ASD. The authors conclude:[226]

> What is clear is that a number of key estimates presented in this report are likely to be much more accurate than those of the previous study.

5.6.2 Cost estimate

The cost of BOD for ASD is simply estimated by multiplying the DALYs (13,866 years) by the VOLY ($281,996), which provides a total estimate of $3,910 million per annum in December 2010 dollars. This is significantly higher than our previous estimate ($766.62 million), due to the higher estimates of DALY and VOLY.

Most of this cost reflects the years of healthy life lost due to disability ($2,257 million per annum), with the remaining $18 million reflecting the cost of premature mortality.

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[225] Begg, S., Vos, T., Barker, B., Stevenson, C., Stanley, L. & Lopez, A. (2007). The Burden of Disease and Injury in Australia 2003, Australian Institute of Health and Welfare, May.

[226] Begg, S., Vos, T., Barker, B., Stevenson, C., Stanley, L. & Lopez, A. (2007). p.132.

5.6.3 Issues and limitations

Clearly, the valuation of quality of life is contentious, and is likely to vary considerably from the perspective of individuals. The method that has been applied is now a generally accepted methodology for valuing the BOD, however will remain highly vulnerable to the underlying assumptions. The estimates produced here are considered conservative, particularly given that the DALYs for ASD that have been estimated for the AIHW are based on prevalence estimates that are below the lower bound that has been applied in this study.

Sensitivity analysis has been performed and summarised in the table below.

Table 15 BOD: sensitivity analysis

Scenario	Estimate (2010$'000)
Base case	3,910,162
VOLY = $340,219 (upper bound Access Economics, 2010)	4,717,477
VOLY = $166,819 (Abelson, 2007 dollars inflated to December 2010 dollars)	2,313,112
VOLY = $80,000	1,109,280
DALYs 20% higher	4,692,195
DALYs 20% lower	3,128,130

This shows considerable variation in the estimates depending on the assumptions used (between $1,109 million and $4,717 million).

5.7 Comorbid conditions

As discussed previously, there is clear evidence to suggest that there are certain conditions that are more likely to occur with ASD, including intellectual disability, mental health problems, depression, epilepsy, obsessive compulsive disorder and tuberous sclerosis complex.

To be treated as an incremental cost of ASD, a clear causal link needs to be established between the condition and ASD. Further, it needs to be demonstrated that the condition is more likely to occur because of ASD. This is extremely difficult to establish for any of the conditions mentioned above, particularly given the underlying causes of ASD itself aren't fully understood.

It is also possible that at least some of the costs of these comorbid conditions have already been included in the cost estimates developed for ASD. This is particularly likely in the case of healthcare expenditure. For example, the study by Birenbaum et al

noted that one of the most common reasons for additional visits to the physician was to monitor seizure disorders.[227]

Additional costs of comorbid conditions have therefore not been included here.

5.8 Overall cost estimates

The cost estimates are summarised in the following tables.

Table 16 Direct costs of ASD per annum

Category	Total cost ($'000 Dec 2010) - low prevalence	Total cost ($'000 Dec 2010) - low prevalence
Healthcare	507,318	859,279
Social services	316,165	316,165
Education	115,964	208,492
TOTAL - DIRECT	**939,447**	**1,383,936**

Table 17 Other tangible costs of ASD per annum

Category	Total cost ($'000 Dec 2010) - low prevalence	Total cost ($'000 Dec 2010) - low prevalence
Employment	1,866,985	3,221,278
Informal care	1,450,050	2,705,683
TOTAL - OTHER	**3,317,035**	**5,926,961**

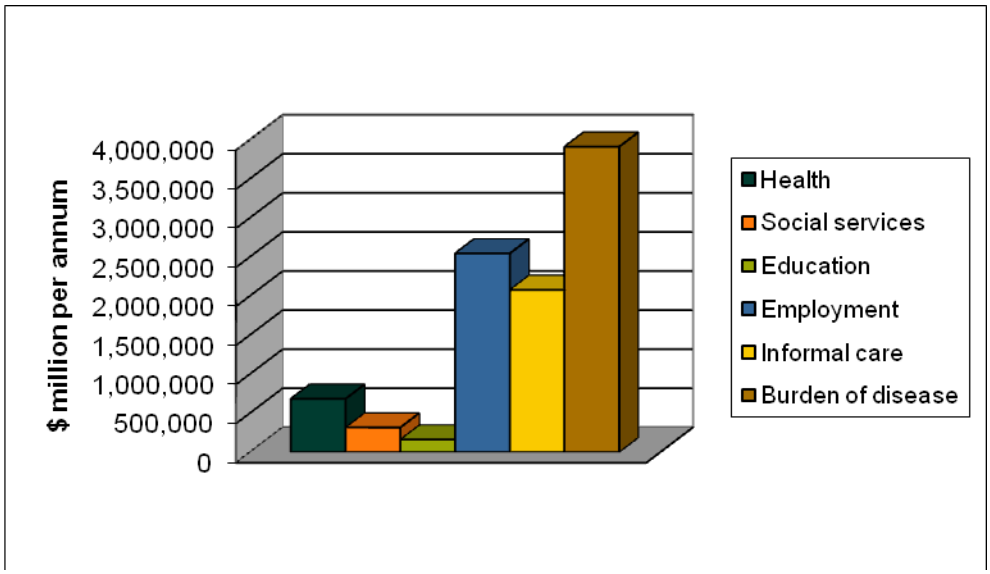
Table 18 Intangible costs of ASD per annum

Category	Total cost ($'000 Dec 2010) - low prevalence	Total cost ($'000 Dec 2010) - low prevalence
Burden of disease	3,910,162	3,910,162

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

[227] Birenbaum, A., Guyot, D & Cohen, H. (1990).

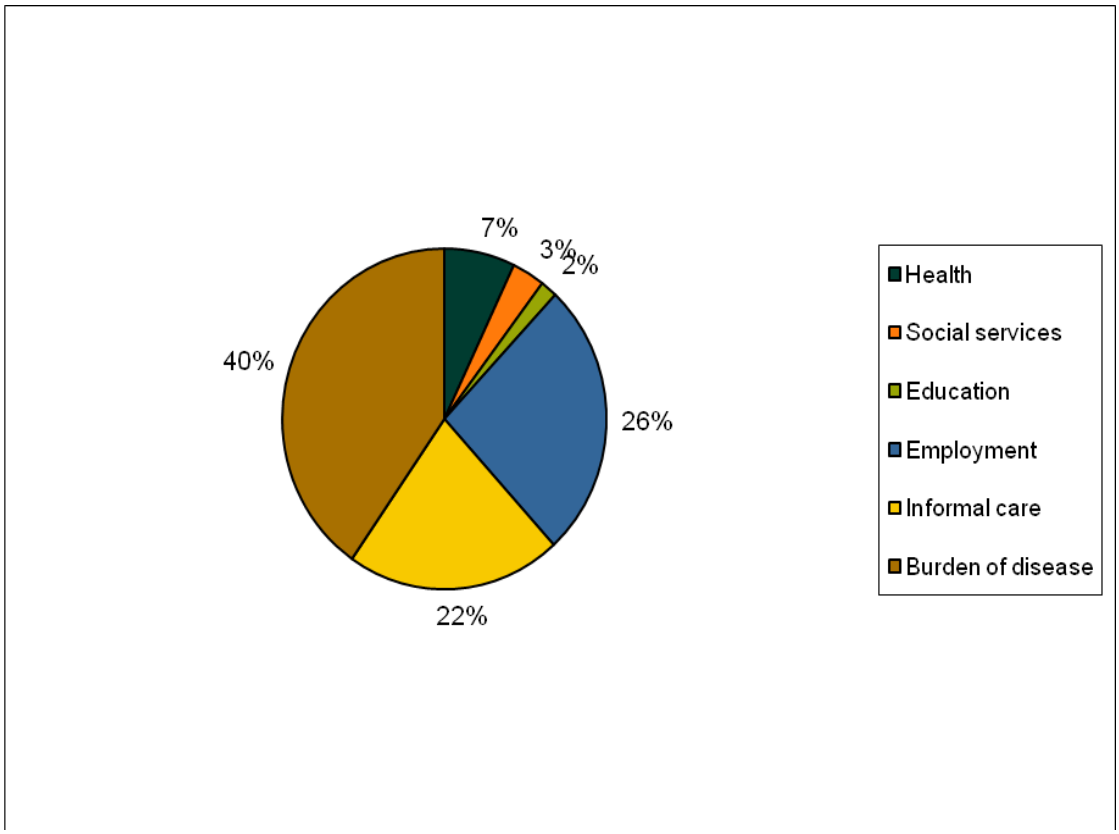
Figure 4 Mid-point of cost estimates by category ($ million December 2010)



The total direct and indirect costs (excluding burden of disease) are between $4.2 billion (low prevalence) and $7.3 billion (high prevalence), with a mid-point of $5.8 billion. The estimated cost of reduced quality of life (or the burden of disease) is an additional $3.9 billion.

Overall, this suggests annual total costs, including burden of disease, of between around $8.1 billion (low prevalence) and $11.2 billion (high prevalence) per annum, with a mid-point of $9.7 billion. This equates to an average incremental cost of approximately $87,000 per person with ASD (based on the mid-point of our assumed prevalence estimates). These costs are not the total costs – it represents the incremental 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.

Figure 5 Relative proportion of each cost category (including burden of disease)



This shows that the most significant cost is the burden of disease. Employment is the next most significant cost, followed by the costs of informal care. Direct costs, being healthcare, social services and education, comprise around 12% of the costs in total.

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 (e.g. healthcare), the total costs were simply allocated proportionately between the conditions. The totals for each are summarised in Table 19.

Table 19 Cost estimates by condition (including the burden of disease)

Condition	Total cost ($'000 Dec 2010) - low prevalence	Total cost ($'000 Dec 2010) - low prevalence
Autism (excluding HFA)	4,812,633	7,549,639
Asperger's/HFA	3,354,011	3,671,420

The cost estimates in this updated study are materially higher than the outcomes of our previous study ($4.5 billion to $7.2 billion in December 2006 dollars). Apart from the impact of inflation, the main driver of this difference is a materially higher burden of disease estimate. This in turn reflects the higher estimate of DALYs, as updated by the AIHW, as well as a higher estimate of the VOLY. For the reasons outlined in section

5.6, we would caution against making direct comparisons with our previous estimates and would not interpret these updated results as suggesting that the economic cost of ASD has materially increased. Instead, these estimates are likely to better capture the economic costs of ASD at the current time.

We consider that our results remain conservative. More recent prevalence estimates from studies that have not yet been published are higher than the estimates we have used here. We have also excluded a number of costs where reliable date could not be obtained (refer section 6). This suggests that our estimates of the economic costs of ASD, while significant, could still be understated.

5.9 Results from other studies

5.9.1 Other costs of ASD studies

There are published studies that have sought to estimate the economic costs of ASD in the UK and US. A UK study by Jarbrink and Knapp (2001) estimated a total annual cost of 957 million (£1997-98), which equates to around $3.8 billion in December 2010Australian dollars.[228]

A more recent study by Knapp, Romeo and Beecham (2009) has also examined the economic cost of ASD in the UK.[229] This estimated an average incremental annual cost of £25,399 per child and £58,877 per adult (2005-06 terms), or $70,738 December 2010 Australian dollars per child and $163,976 December 2010 Australian dollars per adult. The total annual cost to the UK was estimated at £28 billion (2005-06 terms) of $77.98 billion December 2010 Australian dollars. It is noted that both of these UK studies include direct and indirect costs but not the burden of disease.

A US study by Ganz (2006) estimated a total annual cost of $US34.7 billion, or approximately $54 billion in December 2010 Australian dollars.[230]

Caution should be exercised in making any direct comparisons between the estimates produced in each study. While all studies are based on the same cost of illness framework, the methodology underpinning the estimation of each cost component will vary, as will the underlying assumptions (as noted previously, in this study the

[228] Jarbrink, K. & Knapp, M. (2001). The estimates were converted to AUD at the then prevailing exchange rate, before being inflated to December 2010 dollars.

[229] Knapp, M., Romeo, R., & Beecham, J. (2009). Economic Cost of Autism in the UK. Autism, 13: 317.

[230] Ganz, M. (2006).

methodology was largely driven by data availability). Different prevalence assumptions were also applied.

As noted previously, one of the limitations of this study is that it does not show the lifetime distribution of costs. The study has reflected this in the obvious areas, that is:

- education costs were limited to the estimated number of children of school age
- employment costs were limited to people of working age.

Costs of informal care were also limited to people with ASD over 19 years, because it was too difficult to estimate the incremental costs of caring for children with ASD (consistent with the conservative basis for our assumptions).

A 2007 paper by Ganz sought to estimate the incremental lifetime societal costs of people with autism in the US.[231] This is the first known study that has sought to do this and provides some useful insights into the distribution of costs across different age groups and cost categories. It also includes costs not included in our study, such as alternative medicines and behavioural therapies. The concern for our study is less the magnitude of the costs but more how they are incurred through life.

The following table shows the average per capita direct medical costs per age group.

[231] Ganz, M. (2007). The Lifetime Distribution of the Incremental Societal Costs of Autism. Archives of Pediatrics & Adolescent Medicine, Vol. 161, April.

Table 20 Ganz: incremental societal direct medical costs (2003$US)

Age	Physician & dental	Drugs	CAM[a] Therapies	Behavioural Therapies	Emergency & hospital	Home health	Travel
3-7	1,147	147	198	32,501	828	467	81
8-12	577	153	109	4,033	768	303	70
13-17	435	131	50	3,479	591	267	60
18-22	426	129	33	1,254	852	132	52
23-27	496	124	28		774	106	45
28-32	507	114	25		682	87	39
33-37	547	98	21		598	93	33
38-42	540	84	18		522	90	29
43-47	765	72	16		426	137	25
48-52	845	61	14		352	154	21
53-57	851	52	12		292	65	18
58-62	810	44	10		323	14	16
63-66	632	34	9		301	39	14

a Complementary and alternative medicines.

Source: Ganz, M. (2007). The Lifetime Distribution of the Incremental Societal Costs of Autism. Archives of Pediatrics & Adolescent Medicine, Vol. 161, April, p.346.

The most significant cost category is behavioural therapies. These costs are incurred most intensively in the early years, although costs are still incurred through childhood and adolescence. Other costs are incurred throughout lifetime although to varying degrees of intensity. For example, physician and dental costs are initially high in childhood and then decline, before increasing again from the mid-forties. Some costs gradually taper with age. Home health cost peak in the forties.

Table 21 shows the average per capita direct non-medical costs per age group.

Table 21 Ganz: incremental societal direct non-medical costs (2003$US)

Age	Child care	Adult care	Respite care	Home improvements	Special education	Supported work
3-7	46		1,100	161	4,585	
8-12	40		948	139	10,343	
13-17	35		818	120	8,922	
18-22	29		706	10	6,247	
23-27		25,061		9		836
28-32		21,620		8		721
33-37		18,650		7		622
38-42		16,087		6		537
43-47		13,877		5		463
48-52		11,970		4		399
53-57		10,326		4		291
58-62		8,907		3		

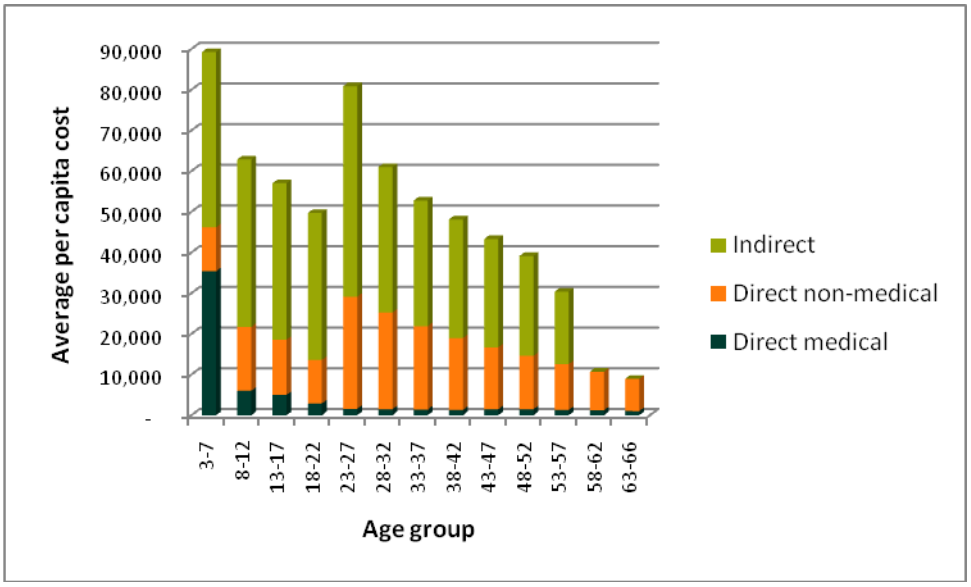
Age	Child care	Adult care	Respite care	Home improvements	Special education	Supported work
63-66		7,423		3		

Source: The Lifetime Distribution of the Incremental Societal Costs of Autism. Archives of Pediatrics & Adolescent Medicine, Vol. 161, April, p.346.

The costs of childcare, respite and special education only apply to children. However, the most significant cost here is the cost of adult care, which peaks in the mid-twenties and gradually declines. Adult care was the most significant lifetime cost for all of the direct costs estimated in Ganz's study.

The total direct and indirect per capita costs by age group are summarised in Figure 6.

Figure 6 Ganz: incremental societal costs of autism (2003$US)



Data source: The Lifetime Distribution of the Incremental Societal Costs of Autism. Archives of Pediatrics & Adolescent Medicine, Vol. 161, April, p.345.

Consistent with our study, Ganz found that indirect costs are higher than direct costs (this does not include the burden of disease). The most significant costs are incurred in early childhood. There are two key drivers here – the costs of behavioural intervention and the indirect costs borne by parents (through unemployment). The costs peak again in the mid-twenties, reflecting the costs of adult care and indirect costs.

What this study also clearly shows is that ASD is not a childhood disorder. Ganz concludes:[232]

[232] Ganz, M. (2007). p.343.

> Although autism is typically thought of as a disorder of childhood, its costs can be felt well into adulthood. The substantial costs resulting from adult care and lost productivity of both individuals with autism and their parents have important implications for those aging members of the baby boom generation approaching retirement, including large financial burdens affecting not only those families but also potentially society in general.

5.9.2 Other costs of illness studies

It can also be compared to studies of the costs of other conditions in Australia, all of which were conducted by Access Economics:

- costs of bipolar disorder (2003)[233]: $1.59 billion per annum
- hearing loss (2006)[234]: $11.75 billion per annum
- cerebral palsy (2008)[235]: $3.87 billion
- youth mental illness (2009)[236]: $31.1 billion per annum.

These estimates include direct and indirect costs, and the burden of disease.

As noted previously, the cost estimates for ASD are considered conservative and a number of costs have not been included due to lack of data. These are summarised in the following section, as well as some suggestions for further work.

[233] Access Economics (2003), Bipolar Disorder: Costs, An Analysis of the Burden of Bipolar Disorder and Related Suicide in Australia, Report for SANE Australia.

[234] Access Economics (2006), Listen Hear! The Economic Impact and Cost of Hearing Loss in Australia.

[235] Access Economics (2008). The Economic Impact of Cerebral Palsy in Australia in 2007, April.

[236] Access Economics (2009). The Economic Impact of Youth Mental Illness and the Cost Effectiveness of Early Intervention, December.

6 Costs not included

The following costs have not been included in this study, mainly because of data limitations.

6.1 Additional costs of ASD

Other conditions on the autism spectrum

The prevalence assumptions applied here include people with autism and Asperger's. The cost estimates will therefore not include people on the autism spectrum that do not fall under either one of these categories, such as those with PDD-NOS.

Early intervention programs

Early intervention has been shown to deliver significant benefits for some children with ASD. However, the total proportion of children with ASD currently enrolled in such programs is not known and the actual need for these services is likely to exceed this. The cost of delivering such a program can be in the order of $40,000 per child per year.

Comorbid conditions

As noted previously, the costs of comorbid conditions have not been included. However, it is possible that there are some costs associated with these conditions that have not been included in the existing estimates for ASD.

The costs of underemployment

Underemployment is a significant issue for people with ASD, particularly for higher functioning conditions such as Asperger's. No estimate of this cost has been attempted here given the lack of data regarding the nature and extent of underemployment. This information would be reasonably difficult to obtain and would best be captured by directly surveying adults with ASD.

Other costs of unemployment

As noted previously, there are other costs arising from unemployment in addition to foregone productivity. These can be significant and are detailed in Appendix B.

Alternative therapies

As mentioned earlier, some families pursue alternative therapies to manage ASD. For example, Ganz cites results of a survey by Green al, which reported that:[237]

> …27% of parents were implementing special diets, 43% were giving their children vitamin supplements, and 26% were using alternative therapies such as aromatherapy and dance therapy.

The extent of this is currently unknown, so the costs have not been captured as part of healthcare expenditure.

Additional education support

The incremental cost estimates for education only captured the costs of special education. There are likely to be other educational supports utilised by parents of children with ASD, including supports for children in 'mainstream' schooling.

Additional living support services

The costs of social services only included expenditure on services currently funded under the CSTDA. There is likely to be a range of other services utilised by individuals with ASD and their families, many of which would be purchased directly by the family. Examples include childcare, personal care, cleaning and home maintenance services and respite.

Cost of informal care for children

The study only included the costs of informal care for adults, given there was insufficient data to estimate the incremental cost of caring for children with ASD. However, it is highly likely that the nature and intensity of caring for a child with ASD is greater, even if the average total hours of care are similar to the hours of care spent by parents caring for children without ASD.

Healthcare costs for family

The outcomes studies examined in section 4 noted that caring for a child or adult with ASD can have significant impacts on the physical and mental health of other family members (particularly the carer). These costs have not been captured here, given the incidence of these health impacts is not known.

[237] Ganz, M. (2006). p.484.

The costs of family breakdown

The outcomes studies for families also revealed a link between caring for a person with ASD and an increased likelihood of family breakdown. The costs of this can be considerable, and are examined more detail in Appendix 7C.

Household repairs and home modifications

The challenging behaviours exhibited by people with ASD may result in damage to homes and cars, requiring repairs to structures, the replacement or cleaning of furniture, and modifications to the home and car etc.

6.2 Suggestions for further work

This study has highlighted a relative dearth of data on the costs of ASD in Australia. Where estimates have been made, a key limitation is that given the absence of data on differential costs by condition and age, an 'average' cost has been applied to the population. In reality, costs will vary considerably between individuals and by age.

Overall, longitudinal outcomes studies are needed to examine the long-term impacts of ASD for Australians. In addition to understanding more about the life 'trajectory' of ASD, and the extent to which it varies between individuals, it will assist in understanding more about the services and supports needed by people with ASD, who in this population is most likely to need them and when they need them. Given ASD is still considered a childhood condition, it is particularly important to understand its implications in adulthood. Prevalence estimates for adults are also needed.

This study is proposed to provide a view on the possible costs of ASD in Australia. It has been limited to desktop research. However, more information on the impacts and costs of ASD could be obtained by engaging directly with people with ASD (and their families). The research instrument developed for this purpose by Jarbrink, Fombonne and Knapp potentially provides a more robust framework for conducting such research.[238]

Finally, there needs to be an increased focus on the systematic collection and reporting of data relating to ASD. This needs to be done in a number of areas, including healthcare, social services and education. Currently, ASD is either not recognised as significant condition (perhaps due to perceptions of relatively low prevalence or its

[238] Jarbrink, K., Fombonne, E. & Knapp, M. (2003).

status as a 'childhood disorder') or is subsumed under other categories, such as intellectual or learning disabilities. This information is valuable as it directly captures the current utilisation of services for ASD and will greatly enhance our understanding of the impact of ASD on individuals and their families.

7 Conclusion

ASD is a lifelong condition that affects a significant number of Australians and their families. Statistics suggest that its prevalence is increasing, although this could simply be due to improvements in diagnostic procedures.

This updated review has produced an updated estimate of the annual economic costs of ASD in Australia as at December 2010, including the burden of disease, of between $8.1 billion (low prevalence) and $11.2 billion (high prevalence), with a mid-point of $9.7 billion.

The total direct and indirect costs (excluding burden of disease) are between $4.2 billion (low prevalence) and $7.3 billion (high prevalence), with a mid-point of $5.8 billion. The estimated cost of reduced quality of life (or the burden of disease) is an additional $3.9 billion. These costs are incremental costs, that is, they only represent the costs incurred for a person with ASD over and above the costs incurred by a person without ASD.

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; and
- 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.

The cost estimates in this updated study are materially higher than the outcomes of our previous study ($4.5 billion to $7.2 billion in December 2006 dollars). Apart from the impact of inflation, the main driver of this difference is a materially higher burden of disease estimate. This is driven by the higher estimate of DALYs, as updated by the AIHW, as well as a higher estimate of the VOLY (based on a 2008 report by Access Economics).

Because these increases are largely a function of methodology differences and/or refinements, we would therefore caution against making direct comparisons with the previous estimates and would not interpret these updated results as suggesting that

the economic cost of ASD has materially increased. Instead, these estimates are likely to better capture the economic costs of ASD at the current time. 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; and
- 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 don't alter the fundamental nature of a person's condition, it could significantly assist them in maximising their capabilities by making best use of the person's strengths, increase living independence and enhance their quality of life; and
- 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.

A Methodological issues

A.1 Measuring economic welfare

From an economic perspective, ASD can be viewed as a condition that reduces economic welfare. That is, we make the assumption that society and particularly individuals diagnosed with ASD would be better off – in an economic sense – without ASD or if the consequences of having ASD were less severe. Standard welfare economics provides an established conceptual framework for measuring these costs, although it is by no means easily implemented.

Assume there are two possible states of the world which vary only by the existence of ASD. Assume further that the cause of ASD became known and it was possible to eliminate the condition. The costs of ASD could be measured by the willingness of people with ASD, or their guardians, to pay for the change. This is known as a compensating variation which is defined as the amount of money we can take away from an individual after an economic change, while leaving them as well off as before the change.

This method would produce an estimate of costs greater than the cost-based approaches discussed below. An individual could pay an amount equal to the money costs they incur from ASD and be no worse off than they were before the change which eliminated it. However, there are some costs associated with ASD for which there is no monetary cost. For example, as parents become older they may experience increased anxiety over the future well-being for their child with ASD. A parent may be willing to pay some amount to remove this anxiety, even though there is currently no monetary cost associated with the anxiety. The willingness to pay for a treatment for ASD is likely to exceed estimates that simply add ASD-related expenditures.

However, there are a number of serious limitations that reduce the practicality of this approach:

- the theory is based on rational choice which is a set of assumptions that describe how economic agents form preferences. These assumptions may not be appropriate for some people with ASD; and
- estimation of willingness to pay is easiest when there is a market for the good and a market price. Adjustments can even be made for price distortions where market prices do not reflect resource costs. However, estimation becomes considerably more difficult when no market values exist. The analyst must use non-market valuation techniques to derive willingness to pay estimates by inferring values

from actual or surrogate markets or using stated preference techniques which employ surveys and focus groups.

As this study will rely on existing studies, and as there are no known willingness to pay estimates available (nor is it necessarily feasible to obtain them), this approach cannot be employed for the study. Others methods will have to be employed, but as discussed above these are unlikely to capture the full impact of ASD on economic welfare.

A.2 Cost-based approach

A cost-based approach is common in the literature. Costs studies measure the costs of expenditures associated with the condition being studied and the opportunity cost which results from the condition.

Cost is equal to the resources required to provide the services specifically related to the condition. Usually the largest area of expenditure is medical expenses. Total expenditures on medical expenses related to the condition (whether by the patient, their family or the government) provide the estimate of economic cost. Other expenditure areas are similarly costed.

The issue of who bears the cost is relevant only so far as to ensure that costs are not double counted. This issue is considered in more detail in the section on pecuniary costs.

A wide variety of cost classifications are observed in the literature (see Table A.1). The division of costs between categories is essentially arbitrary and a simple rather than cost category is preferable. The Access Economics studies use a financial and non-financial cost categorisation. As this is an economic cost study it is preferable to avoid the term 'financial'. The categorisation used by Goeree into healthcare and non-health care and productivity provides the least confusing categorisation.

Table A.1 Classification of costs, selected authors

Author	Area of study	Type of costs
Access Economics	Obesity, Hearing Loss, Bi-Polar Disorder	Direct financial costs, Other financial costs and Non-financial costs
Jarbrink and Knapp (2001)	Autism	Costs for service use, time and productivity, family expenses
Mangalore and Knapp (2006)	Schizophrenia	Health & social costs, Institutional costs, Informal care, Private expenditures, Lost productivity, Criminal justice system, Social security payments
Goeree et al (2005)	Schizophrenia	Healthcare and non-health care costs, Productivity losses

The other category of costs that is considered in most studies is well-being costs. Access Economics describes these as 'non-economic' costs which include the loss of well-being of the individual and as well as family members and carers.[239] The inclusion of these costs is likely to bring a cost based estimate closer to a willingness to pay estimate, although this is an empirical issue. A person's willingness to pay should reflect current expenditures relating to the condition, the value of forgone opportunities and the avoidance of reduced quality of life.

Estimation of these costs applies a standard, although not uncontroversial approach, where the quality of life associated with a condition is quantified using standard factors used internationally.

A.3 Pecuniary costs

Unless the study is particularly interested in showing the distribution of costs, the costs should be the real costs and not pecuniary costs (also known as transfers). A pecuniary change is one that has only a distributional effect. For example, health expenditures are a cost of ASD. If private health expenditures are paid from disability pensions only the expenditures are counted as a cost and not the disability pension that provides the source of income to pay the expenditure. The economic cost associated with transfers, that is, the economic efficiency losses associated with raising the taxation which funds pensions, is a real effect which should be included in the costs.

A.4 Other Issues

Estimates of opportunity costs and well-being costs are expressed in net present value terms, which requires a discount rate to be specified. The discount rate reflects an individual's willingness to trade off current for future consumption or their time rate of preference.

If the future benefits are expressed in real terms, then a real discount rate is used. The commonly used approach to derive a proxy for the time rate of preference is to use a long-term bond rate and subtract from it the expected inflation rate. As opportunity costs are based on expected future wages the real discount rate will need to be adjusted for future productivity growth.

[239] Access Economics (2006). The Economic Cost of Obesity, p.3.

B The Costs of Unemployment

As discussed in the report, one of the potential outcomes for people with ASD is unemployment, including underemployment. This outcome may be a consequence of some of the other outcomes associated with ASD, namely low educational attainment, reduced capacity to manage daily living and reduced social functioning.

The purpose of this Attachment is to provide an overview of the potential economic costs that may result from unemployment. Given data limitations, quantifying these costs is not attempted here. However, it should be noted that these costs are in addition to those determined in the body of the report. The costs of unemployment are potentially significant. Moreover, unemployment is costly not only to the individuals directly affected but also to the economy as a whole.

B.1 Links between Outcomes and Unemployment

Some of the key outcomes of ASD are low levels of educational attainment and poor mental and physical health. These attributes can have a significant impact on employment outcomes. Educational attainment in particular has been clearly linked to employment outcomes.

The link between low educational attainment and unemployment has been clearly established in the economic literature and is supported by statistical evidence. This link is manifest through both unemployment and non-participation in the labour force.[240]

Kennedy and Hedley (2003) identified substantial variations in the labour force participation rate of males and females with different levels of educational attainment.[241] For males, these differences have grown over the past 20 years, with those with no post-school qualifications participating less in the labour force in all age groups. In contrast, female participation rose for all educational attainment categories and for most age groups. Nevertheless, females with a degree or higher qualifications aged 25-64 years in 2001 had participation rates over 20 percentage points higher than those with no post-school qualifications. For both males and females, those who had not completed year 12 schooling had noticeably lower participation rates than those who had completed year 12.

[240] In accordance with the ABS' statistical framework, the 'labour force' encompasses the employed and the unemployed who are available to work within a reference week. All those in the adult civilian population not in these two groups are defined as being 'not in the labour force'.

[241] Kennedy, S. and Hedley, D. (2003). Note on Educational Attainment and Labour Force Participation in Australia, Treasury Working Paper, November 2003.

In an earlier study, Vickery (1999) found that in Australia, as in many other countries, labour market groups with higher skill levels generally enjoy lower unemployment rates.[242] In a review of unemployment and skills across the OECD, Vickery identified that the unskilled unemployment rate is much higher than the skilled rate within each country. While noting that the aggregate unemployment rate had increased substantially in most OECD countries, in each case, the percentage point increase in unemployment has been greater for the less-educated group. This was attributed to two factors: firstly, a less-educated worker has a greater probability of exiting employment each period (that is, a high 'separation rate'); and secondly, once not employed, a less-educated worker has a smaller probability of finding employment (that is, a low 'matching rate').

A 2007 report published by the Productivity Commission (PC) undertook an extensive analysis of men outside the labour force.[243] The findings in this report were consistent with those of the earlier studies cited above, namely that greater educational attainment rates are associated with higher participation rates and lower unemployment risk.

Focussing specifically on males, the research found that boys staying at school for longer grow into men who typically remain active in the labour force at older ages. These findings are reflected in the table reproduced below.

[242] Vickery, J. (1999). Unemployment and Skills in Australia. Research Discussion Paper 1999-12, Reserve Bank of Australia, December.

[243] Lattimore, R. (2007). Men Not at Work: An Analysis of Men Outside the Labour Force, Productivity Commission Staff Working Paper, Canberra.

Table B.1 Labour force analysis by highest educational attainment (%) – males aged 25 to 64 years, May 2005[a]

Attainment level	Full-time work	Part-time work	Unemployed	Studying	Not in the labour force and not studying
Postgraduate degree	80.9	9.2	2.8	1.9	5.2
Grad dip. and graduate certificate	83.6	7.6	1.5	0.9	6.1
Bachelor degree	81.4	8.5	2.2	2.5	5.5
Advanced diploma and diploma	82.0	7.4	2.7	0.8	7.2
Certificate III and IV	81.9	6.4	2.3	0.5	9.0
Certificate I and II	58.5	7.2	9.8	0.0	24.5
Year 12	76.9	9.0	2.8	1.8	9.4
Year 11	78.3	6.9	5.0	0.2	9.5
Year 10 or below	65.5	8.7	5.2	0.3	20.3
Total	**76.9**	**7.9**	**3.2**	**1.0**	**10.9**

a The underlying estimates of the number of males in these categories have a relative standard error of greater than 50 per cent. The underlying relative standard errors for all other categories are less than 25 per cent. Categories may not add to 100 due to rounding.

Source: Lattimore, R. (2007). Men Not at Work: An Analysis of Men Outside the Labour Force, Productivity Commission Staff Working Paper, Canberra.

The PC study found that males with tertiary training have a quarter of the risk of being outside the labour force when aged 25-64 years old than those whose educational attainment is year ten or below. Further, it noted that the returns to education literature typically estimate the percentage increase in annual labour earnings associated with one more year of schooling to be around ten per cent plus or minus four points.[244]

Another key finding of the PC study was the significance of illness and disability as the motivation for detachment from the labour market. It is the main reason for male economic inactivity in Australia for males aged 25-64 years. About one in two males aged between 35-54 years were inactive due to disability or illness. For inactive males aged 25-34 and 55-59 years, the comparable figures are more than one-third. Over all ages from 15-64 years, it accounted for about 26 percent of all inactive men.[245]

[244] This is qualified by noting that these returns do not take account of different effects for different groups of new students. Non-academically oriented male students tend to receive smaller absolute benefits from additional schooling than their academically-oriented peers.

[245] Lattimore, R. (2007). p.99.

Disability is also particularly enduring as a reason for detachment compared with other reasons. More than 90% of males citing disability as a reason for not being in the labour force had experienced a period out of the labour force of over a year.

Further, about one in five of people with disabilities attended school only to year eight or less, compared with less than one in twenty for people with no reported disability. The PC noted that this lower educational attainment leaves them particularly vulnerable to structural changes in the economy.

More broadly, the PC study indicates that illness, injury and disability are associated with adverse effects on educational, social and economic opportunity. As noted by the Australian Institute of Health and Welfare, people with disabilities tend to report lower levels of health, and they tend to have lower incomes than the general population.[246]

B.2 Economic costs of unemployment

The economic costs of unemployment include those costs which fall on the economy and those which accrue to individual unemployed people. Given that some of these economic impacts are immediate and others reflect more indirect consequences, the economic costs of unemployment can be categorised in terms of direct and indirect costs.

B.2.1 Direct costs

The main direct economic costs of unemployment are:

- loss of productive output;
- fiscal costs to government, including both expenditure on social welfare and taxation revenue foregone; and
- individual financial losses.

Loss of productive output

Unemployment causes a waste of scarce economic resources. As such, the consequent loss of productive output reflects the overall losses to the community as a whole through reduced economic growth. In effect, it means the economy does not reach its full productive potential due to the non- or under-utilisation of labour resources. If full

[246] Australian Institute of Health and Welfare (2005). Australia's Welfare 2005, AIHW Cat. No. AUS65. Canberra: AIHW, p. 255.

employment could be reached, output from the economy (GDP) would also increase, leading to an improvement in economic welfare.

The PC noted that foregone economic output is the major economic impact of labour market inactivity. In the study cited above, it provided 'back of the envelope' estimates of the foregone economic output of male inactivity (based on policy changes to realise the economic potential of inactive males)[247] over the next 45 years of cumulatively around $2000 billion (non-discounted). In 2050-51 alone, the gains would be around $90 billion, or about $3000 per capita.[248]

Fiscal costs to the government

Government can incur increased expenditure and face revenue losses due to unemployment. Specifically, fiscal costs to government include the cost of welfare payments made to support unemployed people and their families and taxation revenue foregone due to lower levels of employment. In addition, where unemployed people spend less they contribute less to the government by way of indirect taxes. This rise in government spending combined with a fall in tax revenues may result in a higher government borrowing requirement.

Estimating the fiscal costs to government is complex and depends on a number of assumptions. For example, assumptions need to be made about the extent to which unemployment affects the demand for a whole range of income support payments (such as disability support, sole parent payments and sickness benefits), and not just unemployment benefits. Assumptions also need to be made about the 'counterfactual' – that is, what would be a 'natural' level of unemployment which would occur in any event, and what level of earnings previously unemployed people would achieve.[249]

In addition to the cost of welfare payments, there is an efficiency cost to the economy associated with raising taxes. This is known as the deadweight costs of taxation, and it reflects the economic efficiency loss caused by distortionary taxation.

Individual financial losses

Clearly a direct impact of unemployment is the loss of personal income to unemployed people and their families. While this costs appears distinct in that it impacts at an

[247] The PC noted that the key to understanding the net economic costs of labour market inactivity is a comparison of outcomes under current inactivity rates with a realistic counterfactual that reflects the best achievable rate of re-engagement.

[248] Lattimore, R. (2007). p. 117.

[249] Eardley, T., "Identifying and Quantifying the Costs of Unemployment" in Saunders, P. and Taylor, R. (2002). The Price of Prosperity, The Economic and Social Costs of Unemployment, UNSW Press.

individual, rather than economy-wide level, personal income loss cannot be aggregated with those sustained through loss of productive output and fiscal costs to government as this would result in double counting.

B.2.2 Indirect Costs

There are also a number of indirect costs that may arise due to unemployment. These reflect negative social outcomes that may be associated with unemployment, such as ill health, crime and family breakdown. Generally, rising unemployment is linked to social and economic deprivation. Adverse social outcomes that may be linked to unemployment include:[250]

- poverty
- poor health
- premature mortality
- psychological stress and suicide
- criminal behaviour
- loss of human capital
- family breakdown.

However, it should be noted that, where an association is established between unemployment and adverse social outcomes, it is difficult to determine the direction of causation – that is, whether unemployment has caused the condition or vice versa. It can also be more difficult to assign dollar values to these costs. Despite this, such costs do exist and may in fact be greater than the direct economic costs. Examples include the costs of increased demand for health services or additional expenditure on the criminal justice system. In addition, many of these social effects are very long-term and therefore likely to persist.[251]

An overview of these indirect effects of unemployment is provided below.

Poverty and inequality

The loss of income that is directly linked with unemployment will increase the risk of poverty faced by unemployed people and contribute to social inequality. Saunders

[250] Eardley, T., in Saunders, P. and Taylor, R. (2002).

[251] Eardley, T., in Saunders, P. and Taylor, R. (2002).

(2002) noted that there is broad agreement in the literature that poverty, income inequality and social exclusion is closely linked to unemployment.[252] Further, it is not merely the existence of unemployment which is an issue but also the burden, including its higher concentration within families and particular communities and its duration. When unemployment is entrenched among specific social groups and areas, its social consequences are more serious.

The McClure Report to the Australian Government, which reviewed the welfare system, identified the existence of entrenched economic and social disadvantage linked with unemployment, noting that long term economic and social disadvantage has negative consequences for individuals, their families and the broader community.[253] The report noted that lack of paid employment during the prime working years and consequent reliance on income support reduces current and lifetime incomes.

There is evidence that unemployment in Australia is becoming more concentrated in family units. Miller (1997) found that, by the 1990s, the situation where both husband and wife were unemployed had become a reasonably common feature of society, with one couple family in 100 having both spouses unemployed.[254] Given this concentration, any given level of unemployment poses a much more serious social and economic problem.

This is particularly so when the impact on children is taken into account. The McClure Report cited a 1999 longitudinal study of social security data by Pech and McCoull that showed that, between the ages of 16 and 18, young people from income support recipient families are much more likely than other young people to become parents at an early age, leave school early, receive income support and be highly income support reliant themselves.

Participation in employment is also recognised as a major source of self-esteem. Without employment, people can fail to develop or become disengaged from employment and family and community networks, leading to physical and psychological ill-health and reduced life opportunities for parents and their children. Long term unemployment is also associated with loss of skills, reducing the chances of a successful return to work in the future. Moreover, similar to jobless families, concentration of unemployment in 'job poor' communities can be self-reinforcing, with

[252] Saunders, P. , "The Impact of Unemployment on Poverty, inequality and Social Exclusion", in Saunders, P. and Taylor, R. (2002).

[253] McClure (2000). Participation Support for a More Equitable Society, Final Report.

[254] Miller, P. (1997). The Burden of Unemployment on Family Units: An Overview. The Australian Economic Review, 30(1), pp.16-30.

the most disadvantaged regions having poorer educational, social and transport infrastructure and reduced employment opportunities.[255]

Health effects

There is significant evidence to show a strong relationship between unemployment and health. This link has been demonstrated for some specific causes of death (such as diabetes, pneumonia, influenza and bronchitis) as well as for a number of specific chronic illnesses. Unemployment has also been shown to cause certain forms of mental illness, such as depression (McClelland and Macdonald, 1998).[256]

In a review of the Australian and international evidence for an association between unemployment and adverse health outcomes, Mathers and Schofield (1998) concluded that, although the relationship between unemployment and health is complex and varies for different population groups, there is consistent evidence from different types of studies that unemployment is associated with adverse health outcomes.[257] While noting that health 'selection effects' do occur, the evidence is reasonably convincing that unemployment has a direct effect on health over and above the effects of socio-economic status, poverty, risk factors or prior ill-health.

The PC study discussed above provided an overview of the evidence from a number of studies on the relationship between labour market status and mental health, including that:[258]

- joblessness increases perceptions among those affected of alienation and rejection from society, failure, low self-esteem, lack of purpose and pessimism, which intensify with duration;
- the impacts of more severe psychological conditions, such as depression, have also been linked to labour force status. One study found that those who lose their job have over twice the risk of depressive symptoms and clinical depression; and
- for income support recipients (of which those outside the labour force are a large group), over one-third reported anxiety, depression or a substance abuse disorder, compared with 19 per cent of non-recipients.

[255] McClure (2000). p.3.

[256] McClelland, A. & Macdonald, F. (1998). The Social Consequences of Unemployment, Report for the Business Council of Australia.

[257] Mathers, C. & Schofield, D. (1998). The Health Consequences of Unemployment: The Evidence. The Medical Journal of Australia, 168.

[258] See Lattimore, R. (2007). pp. 130-132 for references to individual studies.

Family life

Unemployment can also have a significant impact on affected families. These effects include intergenerational impacts, welfare dependence and financial and emotional strain on families, including strain on relationships.

There is growing evidence that joblessness and welfare reliance among adults are associated with poorer subsequent labour market prospects for their children. Parental traits that increase the likelihood of joblessness or that stem from it also affect the skills, attitudes and behaviours of their children. For example, children of jobless, welfare-reliant parents are less likely to complete secondary schooling and more likely to be welfare reliant themselves.[259]

Identifying separation and divorce as an indicator of family strain, the PC cited data which showed that 15-64 year old males outside the labour force have separation and divorce rates that are similar to the unemployed, and much higher than the employed. The difference between the jobless and employed is more notable for men aged 45-54 years, with those men outside the labour force having approximately double the divorce rate of those who are employed. In addition, a much greater proportion of such men have also never married compared with employed males.[260]

Unemployment, particularly where it is concentrated in families, can have long term effects. In 1997, 17.9% of children under 15 years were in families with no parent in paid employment. This increasing concentration of unemployment in family units will have long term consequences for their educational, employment and social futures. Given this concentration, any given level of unemployment poses a much more serious social and economic problem.[261,262]

Some of the indirect social effects of unemployment are captured in the following comment on long-term unemployment:[263]

> The real financial, psychological and economic damage is caused by being unemployed for prolonged periods. Then savings and lines of credit are exhausted; assets, including the family home, might have to be sold; people become depressed by repeated failures in their job applications; skills atrophy and there is a build up in stress within the family, that can lead to violence and family breakdown. There is

[259] Lattimore, R. (2007). p. 135.

[260] Lattimore, R. (2007).

[261] McClelland, A. & Macdonald, F. (1998).

[262] Miller, P. (1997). pp.16-30.

[263] Richardson, S (2004). Unemployment in Australia, Academy of the Social Sciences in Australia.

strong evidence that the longer a person is unemployed, the lower the chance they have of finding a job in the next period.

Crime

Higher crime rates are also cited as one of the potential indirect impacts of unemployment. Crime participation is often linked to labour force status, with many studies finding evidence that higher unemployment raises crime rates (although there is little evidence of similar links to labour force inactivity).[264] In a US study analysing the relationship between unemployment and crime, results consistently indicated that unemployment is an important determinant of property crime rates.[265]

A more recent review of the link between unemployment and crime in an Australian context concluded that, generally speaking, otherwise law-abiding individuals do not respond to unemployment by becoming involved in crime. The short-run effects of a rise in unemployment are likely to be influenced by a number of factors, including:

- whether the unemployment occurs principally among young, unskilled, low socio-economic status workers;
- whether those most affected are or have previously been involved in crime;
- whether the economic returns from crime exceed those from legitimate employment; and
- whether the average period of unemployment is long or short.

The review indicated that the long term effects of unemployment on crime are more subtle, but potentially more significant. Chronic unemployment, particularly where it is spatially concentrated, was identified as having two likely effects: cutting young people off from access to information about legitimate income-earning activities, while enhancing their access to information about illegitimate activities; and increasing the level of economic stress on families with dependent children. This stress is disruptive to parenting, increasing the risk that children exposed to this will later become involved in crime.[266]

[264] Lattimore, R. (2007). p. 139.

[265] Raphael, S. & Winter-Ebmer, R. (2001). Identifying the Effect of Unemployment on Crime. The Journal of Law and Economics, vol. XLIV.

[266] Weatherburn, D. "The Impact of Unemployment on Crime", in Saunders, P. and Taylor, R. (2002). p. 226.

B.2 Summary

The economic costs of unemployment include both direct impacts on the economy, such as loss of productive output and welfare payments, and indirect impacts on affected individuals and society as a whole. While it is difficult to establish in some instances the direction of causation of indirect effects, such as impacts on health, family and crime rates, there is considerable evidence of links between unemployment and these adverse social outcomes.

C The Costs of Family Breakdown

C.1 Introduction

As noted in section 4.2, there is evidence to suggest that the stress of caring for a child or adult with ASD can increase the risk of family breakdown. This Appendix provides an overview of some of the possible impacts of family breakdown. These impacts (directly and indirectly) impose a cost on affected individuals and society. These costs, although difficult to quantify, encompass financial costs to individuals and society as well as indirect costs that manifest through the impact family breakdown has on an individual's health and well-being and, particularly, on children.

C.2 Family breakdown

In a 1998 report by the Standing Committee on Legal and Constitutional Affairs on an inquiry into aspects of family services, several possible manifestations of relationship dysfunction were noted. These included family violence, child abuse and youth homelessness.[267] Less severe manifestations may also occur, such as emotional distress and strain on family members, potentially affecting health and functioning at work and school.

Research has indicated some common factors associated with marital breakdown, including:[268]

- unemployment and work related issues; and
- high risk factors within marriages, such as addictive behaviours, chronic illness or death of a child, domestic violence, poor communication skills.

That is, the existence of such underlying social issues as poverty, mental illness, substance abuse and unemployment can result in abuse and neglect within families and lead to breakdown.

A 1984 study analysed rates of family breakdown associated with particular characteristics.[269] It noted that research identified a fairly stable and consistent set of factors that appear to be related to rates of marital breakdown. These can be categorised as factors relating to patterns of family formation (marrying young,

[267] Standing Committee on Legal and Constitutional Affairs, House of Representatives (1998). To Have and to Hold: Inquiry into Aspects of Family Services, Parliament of Australia, pp. 47-49.

[268] Clifford, R. & Nickson, A. (2002). Exploring Extreme Family Breakdown.

[269] Fergusson, D., Horwood, D., & Shannon, F. (1984). A Proportional Hazards Model of Family Breakdown. Journal of Marriage and the Family, 46(3), pp. 539-549.

marrying as a result of premarital conception) and family social background (rates of marriage breakdown have been found to be highest among families of low socioeconomic status, families in which unemployment is recurrent or chronic and in families with poor educational levels). The study noted that the empirical research suggested a 'cumulative disadvantage' model of family breakdown, such that a family's likelihood of dissolving is related to the number of adverse family formation, social and other factors that are present.

A recent study by Silvey and Birrell (2004) examined the financial circumstances of separated parents who were registrants of the Australian Child Support Agency (CSA) at the time of separation and who remained registrants for at least four years.[270] The main conclusion was that the fathers registered with the CSA were predominantly drawn from men on incomes which average well below those of all men in their age group. The authors concluded that low income is an important factor in separation and is clearly associated with strains on a married partnership.

C.3 Impacts of family breakdown

Family breakdown has both direct and indirect costs. Direct costs include the economic cost associated with additional welfare payments, family court costs, legal aid, the child support scheme and taxation rebates. Indirect costs arise from the potential impact of family breakdown on affected individuals on other aspects of life including health, education and employment.

C.3.1 Direct costs

In the 1998 inquiry into aspects of family services cited above, an estimate of the direct cost to the Commonwealth Budget of marriage breakdown was calculated based on the cost of a range of programs and income support measures.[271] The total figure estimated was $2,771 million per annum. The report indicated that this was likely to be conservative as certain other expenditures, such as emergency accommodation and the homeless allowance, were unable to be estimated and the expenditure by State and Territory government, local councils and charitable organisations was not included.

[270] Silvey, J. & Birrell, B. (2004). Financial Outcomes for Parents After Separation. People and Place, 12(1).

[271] For example, expenditure on the Sole Parent Pension, Child Support Scheme, Family Court costs, Legal Aid expenditure on Family Court cases and the cost of the Sole Parent Tax Rebate.

Financial impact on individuals

There is a significant body of research addressing the economic and financial costs of relationship breakdown on individuals. Studies typically employ one of several measures to document the economic consequences of separation and divorce: poverty rates, per capita income, family income and the ratio of income to needs.

One common theme to emerge is that the economic costs of divorce are greater for women. Poverty rates for women in the year following divorce are uniformly higher than during marriage. However, men seem to experience an increase in economic well-being after divorce. Women without partners are worse off economically than married peers and households headed by women are more likely to be poor than those headed by males.[272]

An Australian study examined the financial consequences of divorce on older Australians (aged 55-74 years).[273] It found that, on average, having been divorced had negative consequences for income in older age for both men and women. However, it also noted that the negative financial impacts of divorce were substantially lessened by remarriage.

This study examined the impact of divorce in later life through analysis of certain measures of financial living standards, including annual household income, housing tenure, superannuation and receipt of income support payments. The results for the following measures are:

Home ownership:

- three quarters of the married never-divorced men owned a home outright, compared to just 40.9% of the divorced single men and 57.8% of the divorced and remarried men (the pattern was similar for women);

Assets:

- divorced single men and women had lower median levels of per capita household assets than those who were married and never divorced;

[272] Holden, K. & Smock, P. (1991). The Economic Costs of Marital Dissolution: Why Do Women Bear a Disproportionate Cost? Annual Review of Sociology, 17.

[273] de Vaus, D., Gray, M., Qu, L. & Stanton, D. (2007). The Consequences of Divorce for Financial Living Standards in Later Life. Research Paper No. 38, February 2007, Australian Institute of Family Studies.

Income:

- for older men, the median household equivalent income was lowest for divorced single men ($15,500), followed by married never-divorced men ($24,500) and was highest for those who had divorced and remarried ($28,900);
- divorced and single men and women received higher levels of income support payments (including the age pension) than either the divorced and remarried or the married never-divorced;

Perceived prosperity and material hardships:

- older divorced single Australians are much more likely to experience material hardships than the married never-divorced;
- for both men and women, the divorced and single reported having a lower level of prosperity than the married never-divorced.

Reasons for this negative impact of divorce on retirement incomes include: the effects of divorce on asset accumulation; the impact of legal fees incurred in negotiating property settlements; and the increase in living costs when a family separates (related to the loss of economies of scale).

The study noted the extensive literature on the impact of divorce on the specific financial circumstances of women, in particular, that studies from a number of countries have found that women experience a decline in financial circumstances following divorce. It is generally argued that the negative impact is greatest for women who have had children, since these women are the least likely to have a strong labour market position to enable them to recover financially.

The study noted that divorce impacts on financial circumstances in the following ways:

- it will normally result in the creation of two households rather than one, potentially leading to a decline in living standards and to the loss of economies of scale, which in turn make it more difficult to save and accumulate assets;
- it may affect labour force participation. In some cases, it may lead to withdrawal from the labour force (e.g. to enable a lone parent to care for children). In other cases, it may require a person to re-enter the workforce or stay in the workforce longer than they may have intended so that they can accumulate sufficient funds for retirement; and
- the amount of the age pension (and most other government support income) depends on relationship status.

C.3.2 Indirect costs

There is considerable evidence to indicate that family breakdown has significant indirect effects, particularly in terms of health consequences and the adverse impact on children. These indirect costs are difficult to quantify, but are nonetheless potentially significant.

Impact on health

A considerable body of evidence indicates that both adults and children are at increased risk of mental and physical problems due to marital distress. The 1998 report by the Standing Committee on Legal and Constitutional Affairs noted that virtually every study which has analysed mortality rates by marital status shows that the unmarried have higher death rates. For a number of illnesses, the report cited evidence of increased mortality among the divorced and separated.

A survey of the literature by McAllister noted that marital status has long been identified as one of the social characteristics associated with heart disease and stroke. It was also noted that, as is the case with cancer, there is also evidence of superior survival rates following myocardial infarction among the married, in comparison to other marital status groups.[274] The report noted that Australian studies support these conclusions.

The report also noted evidence that relationship breakdown is one of the major causes of suicide worldwide, reflecting the loss and depression often associated with divorce and separation. It cited evidence from McAllister that the divorced have a three to four fold higher risk of suicide than the married. In terms of morbidity, both perceived physical and mental health have been found to be related to marital status in a way similar to mortality.

The report cited the conclusion by Professor Doherty that marital distress is an important health hazard for adults and children, leading to depression and reduced immune system functioning in adults. In addition, chronic marital conflict harms the emotional and physical well-being of children.[275]

[274] McAllister, F. (ed) (1995). Marital breakdown and the Health of the Nation, London: One plus One, cited in Standing Committee of Legal and Constitutional Affairs. p.29.

[275] Doherty, W. (1997). The Scientific Case for Marriage and Couples Education in Health Care, paper University of Minnesota, cited in Standing Committee of Legal and Constitutional Affairs. p. 34.

Impact on children

Children suffer a range of adverse consequences from family breakdown. The study by Clifford and Nickson concluded that the evidence indicates a number of recurring themes:[276]

- children from single parent families, or whose birth parents separate are at increased risk of adverse educational, health and behavioural outcomes compared with those from similar backgrounds in unbroken two-parent families;
- research has found prevalence of physical abuse to be twice as high in single parent families than two parent households;
- children who live with their mothers after separation or divorce are likely to experience reduced contact with their father and suffer distress from this loss; and
- higher rates of behavioural issues.

The report by the Standing Committee on Legal and Constitutional Affairs noted that a large number of studies have shown that divorce has both a short-term and a long-term impact on children and that this impact often extends into adult life with consequences for health, family life, educational performance and occupational status. It cited research findings from a range of studies that:

- adolescent children in divorced lone mother families and in stepfamilies formed through remarriage consistently scored less well on indices of behaviour, competence and education than comparable children whose parents were stably married;[277]
- there is evidence of increased behavioural problems and delinquency among both boys and girls whose parents divorced;[278]
- the educational performance of children is adversely affected;[279] and

[276] Clifford, R. & Nickson, A. (2002).

[277] Hetherington, M. & Clingempeel, W. (1992). Coping with Marital Transitions. Monographs of the Society for Research in Child Development, Series 227, Vol. 57, No. 2-3, Chicago: University of Chicago Press, cited in Standing Committee of Legal and Constitutional Affairs. p. 35

[278] Standing Committee of Legal and Constitutional Affairs. pp. 36-37.

[279] Standing Committee of Legal and Constitutional Affairs. p. 38.

- evidence from a British longitudinal study found that the impact of divorce may be long-term, with the experience of divorce as a child potentially having adverse effects in terms of health, behaviour and economic status in later life.[280]

These identified differences in outcomes have typically been attributed to either the economic and parental resources available to children or to the stressful events and circumstances to which children must adapt.[281]

C.4 Summary

Family breakdown can have a direct economic impact on affected individuals and society. These can include the impact on individual wealth and financial circumstances and the budgetary cost of government programs designed to address this issue. Research also indicates that there are also likely to be indirect effects of family breakdown, particularly in terms of the health of affected individuals and the impact on children. These impacts are likely in turn to give rise to economic costs.

[280] McAllister, F. (ed) (1995). p. 35-36.

[281] Amato, P., (2005). The Impact of Family Formation Change on the Cognitive, Social and Emotional Well-Being of the Next Generation. The Future of Children, 15 (2), Fall 2005.

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