The Economic Benefits of Early Intervention for Children with Disabilities

A Report for the Not for Profit Children's Lobby Group

February 2012
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Executive Summary

Purpose

Synergies Economic Consulting (Synergies) has been asked to prepare a report for the Not for Profit Children’s Lobby Group on the economic benefits of early intervention for children with disabilities. As part of this review we have been asked to focus on five specific disabilities, being:

- Autism Spectrum Disorder
- Cerebral Palsy
- Down syndrome
- Hearing impairment
- Visual impairment

The first three conditions are multi-dimensional in nature (that is, the child is likely to have impairments in more than one functional area). Apart from the challenge presented in examining the five different disability types, analysis of data from the three comparatively multi-dimensional conditions is more difficult to interpret due to the wide range and severity of the primary impairment in each case, as well as the wide range and severity of associated and secondary conditions commonly observed.

The review examines the specific nature of each of these disabilities and how early intervention has the potential to benefit children that are diagnosed with them. Although it is not intended to comprehensively cover all disability types, in representing some of the main disabilities affecting children in Australia this review will inform a general assessment of the potential role of early intervention in the lives of children with disabilities and their families.

The Productivity Commission’s Final Report on Disability Care and Support\(^1\) recommends the building of an evidence base for early intervention strategies, as well as undertaking economic analysis such as cost-benefit analysis. It also recognised the issues in developing a robust evidence base for early intervention, in particular, longitudinal studies for children who have received early intervention that track outcomes well into their adult life. This report responds to this recommendation by providing a starting point for this economic analysis.

Early intervention theory and practice

‘Early intervention’ is an umbrella term that is used by various service providers to represent a heterogeneous range, combination and intensity of services and treatments employed to meet the needs of individual children with a range of primary conditions and associated problems and their families. Therefore, there is no blanket early intervention strategy that is either effective or appropriate for all children under all circumstances.

Early intervention can be delivered in a number of different ways, depending on the nature of the child’s impairment/s, as well as the family and community environment in which the child lives. While this report will refer to different intervention practices, as well as what is currently known about the general principles underpinning good intervention practice, it does not provide a comprehensive review of these strategies, nor will not seek to evaluate or compare them.

Early intervention is not simply advocated for its own sake – intervention practices need to have a robust foundation in developmental theory and what is known about the effectiveness of different intervention strategies. They also need to be implemented in a manner that is consistent with what is known about best practice, that is, there needs to be a focus on service quality. Programs also need to be appropriately targeted to the needs of the child and the family, recognising the environment in which the child lives. Not all strategies will be effective for all children, and the family environment and other circumstances can also have a significant impact on the outcomes that are realised.

There has been significant advances in early intervention research and practice in recent decades. In particular, advances continue to be made in understanding the underlying science. We now know considerably more about early development and hence where and why early intervention has the potential to positively influence outcomes for children with disabilities and their families.

A summary of the more recent literature on efficacy and effectiveness for the five disabilities that are within the scope of our review are contained in the Appendices, focussing on effectiveness studies where possible. We must emphasise that our review, while not intended to be comprehensive, shows that there is an empirical foundation for the benefits of early intervention.

In order to be able to measure the long-term benefits of early intervention within a cost-benefit framework, we require robust studies (that is, studies with an appropriate methodological design) providing evidence of the extent to which early intervention influences long-term outcomes for the child (and their family).
Based on our review, this long-term outcomes evidence is currently not available. However, particularly given the strong foundation for early intervention that has already been built, it is clear that it has the potential to generate significant long-term benefits. It is expected that this evidence base will be augmented by long-term effectiveness studies in the future.

In the absence of this long-term outcomes evidence, this report provides a starting point by outlining the economic framework that can be used to assess the benefits, as well as showing what these benefits might look like under a number of different scenarios.

**Methodology**

This report employs a cost-benefit analysis framework to assess the benefits of early intervention.

Benefit-Cost Ratios (BCRs) will be estimated based on indicative costs of early intervention. We have not sought to develop population estimates of the costs and benefits as amongst other things, it would require robust data on the following:

- the number of children with the disability that are enrolled in early intervention programs in each year;
- the types of early intervention received; and, most importantly
- the range of long-term outcomes that are likely to be experienced across that group of children, reflecting the differences in the number and nature of the impairments as well as the effectiveness of specific intervention strategies.

As outlined above, there is not sufficient evidence regarding the impact of early intervention on long-term life outcomes. We have therefore sought to estimate the potential benefits that could be generated for a child who undergoes early intervention, relative to the indicative costs of providing that child with early intervention. In essence, the benefits are the avoided future costs associated with a particular disability and the increased economic output resulting from the improvement in productivity if workforce participation is increased.

For an investment to be ‘net present value positive’, the benefits need to exceed the costs (and not by any threshold order of magnitude). A common measure that is used is BCR. If the ratio of benefits to costs is greater than one, the investment will yield positive economic benefits.

The starting point for establishing the benefits of early intervention is the potential lifetime trajectory for a person with the particular disability who has not received any
Early intervention. The key areas we will focus on that can potentially be quantified are as follows:

1. education
2. employment
3. living independence
4. healthcare
5. quality of life.

Early intervention can also have a significant impact on families. We have not been able to quantify this impact but it should still be recognised.

Importantly, the analysis is an incremental analysis. The benefits and costs that are identified should only be those benefits and costs that directly arise as a consequence of early intervention. For example, in the case of costs we would exclude costs that could otherwise be incurred for a child with that disability in the absence of early intervention.

A brief overview of the approach that is taken to measuring benefits in each of the above areas is provided in the table below. The approaches are somewhat limiting however this reflects the availability of data. In hypothesising outcomes we emphasise that they will not be the outcomes for all people with disabilities – some will achieve better outcomes and others worse.

<table>
<thead>
<tr>
<th>Methods used to estimate benefits in each area</th>
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<tbody>
<tr>
<td><strong>Area and possible outcomes</strong></td>
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<tr>
<td><strong>Education</strong></td>
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<tr>
<td>Base case: Children with disabilities may need to attend a special school, or attend a mainstream school with additional support.</td>
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<tr>
<td>Impact of early intervention: The types of scenarios we have considered include where:</td>
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<td>• a child that would have attended a special school is able to attend a mainstream school, with or without support</td>
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<tr>
<td>• a child that would have attended a mainstream school with support is able to attend that school without support</td>
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<tr>
<td><strong>Employment</strong></td>
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<td>Base case: A person with a disability may be unable to secure a job (unemployment) or may be able to secure a job but it does not allow them to fully utilise their skills and capabilities (underemployment). Employment outcomes will have some relationship with educational outcomes.</td>
</tr>
</tbody>
</table>
**Quality of life**

**Base case:** A disability can adversely impact a person’s quality of life. The World Health Organisation has developed a methodology to assess the reduction in quality of life as a consequence of illnesses and impairments. A key metric emerging from this is the Disability Adjusted Life Year (DALY), which combines the years of healthy life lost due to disability with the years lost through premature mortality.

Of key interest to us are the years of healthy life lost due to disability (premature mortality is clearly a significant issue but is difficult to assess). This is measured by the disability weight. These weights range from 0 (which means living in a state of good or ideal health) to 1 (which is equivalent to death). For example, if a disability is assigned a weight of 0.5, it means that for each year of life, the equivalent of half a year of healthy life is lost due to disability. This in turn is seen to proxy the impact of disability on a person’s quality of life. The impact on morbidity has not been examined.

**Impact of early intervention:** To the extent that early intervention improves a person’s quality of life, we can estimate these quality of life improvements by hypothesising possible reductions in the disability weight.

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**Health care**

**Base case:** Children with disabilities may suffer a range of other health problems compared to children without disabilities.

**Impact of early intervention:** Early intervention may improve health care outcomes for children with a disability.

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**Living independence**

**Base case:** A person with a disability may require assistance with daily living activities throughout their adult life. Some will not be able to live independently. This assistance is provided through formal care services and informal care by family members and communities.

**Impact of early intervention:** To the extent that early intervention can improve a person’s ability to carry out daily living tasks and even perhaps live independently, the costs of formal and informal care can be avoided or reduced.

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<table>
<thead>
<tr>
<th>Area and possible outcomes</th>
<th>Method</th>
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<tbody>
<tr>
<td></td>
<td>consequence but they are transfers within the economy. They are not captured to avoid double-counting.</td>
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<td></td>
<td>The benefits of a reduced reliance on formal care can be estimated based on the avoided costs per person, based on published data regarding the costs of services in Australia. There are two approaches we have looked at to estimate the benefits of reducing reliance on informal care. These are:</td>
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<td></td>
<td>• the opportunity cost method, which measures the wages foregone by the carer as a result of that carer’s inability to participate in the workforce (or participate based on hours that are less than what they would otherwise want to work). Similar to employment, this measures the productivity impact of carers withdrawing their labour from the workforce;</td>
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<tr>
<td></td>
<td>• the replacement cost method, which attempts to value the output of informal care by applying the market wage of a caregiver in the formal sector to informal care. Applying the opportunity cost method requires assessing whether the reduced reliance on informal care allows the carer to participate in the workforce. The replacement cost method assumes that a reduced reliance on informal care reduces the cost of providing that care, by attributing a market rate to each hour of care provided per week.</td>
</tr>
<tr>
<td></td>
<td>To the extent that there is a direct link between early intervention and improved health care outcomes, the benefits can be assessed as the reduced or avoided health care costs.</td>
</tr>
</tbody>
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**Table 1**

<table>
<thead>
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<th>Area and possible outcomes</th>
<th>Method</th>
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<tr>
<td></td>
<td>The annual cost of reduced quality of life from disability can be measured by multiplying the disability weight by the value of a life year. While putting a value on a year of healthy life is clearly difficult, published studies are available that seek to estimate what a person would be willing to pay for health (on average). These estimates are used by policy makers in making decisions. The benefits of an improvement in quality of life can therefore be estimated by multiplying the hypothesised reduction in the disability weight by the value of a life year. This is an estimate of a cost that is therefore reduced as a consequence of early intervention.</td>
</tr>
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**Synergies**

**Economic Consulting**
Benefits and costs of different outcomes scenarios

Approach

It is clearly evident from our review of the literature that outcomes can vary considerably between disabilities and for any group of children with the same disability. This is particularly the case for multi-dimensional conditions such as ASD, Cerebral Palsy and Down Syndrome. Some variation can also be expected for hearing impairment and visual impairment (which are uni-dimensional in nature), however in the absence of comorbid conditions the range is unlikely to be as wide.

As outlined above, on the whole, robust data linking specific intervention strategies to long-term outcomes for children who have received early intervention is lacking. However, the efficacy and effectiveness studies that have been published suggest that positive outcomes are plausible. In the absence of this data we consider that a reasonable starting point for evaluating the costs and benefits is to hypothesise alternative scenarios that are considered plausible based on what is known about early intervention for children with disabilities. These scenarios consider combinations of outcomes in the key life areas.

We do not consider that it is realistic or appropriate to present a single overall range of outcomes. A key reason for this is that the outcomes will depend on the individual’s level of functioning prior to intervention, as well as their response to intervention (apart from other factors), cultural norms and their own individual life goals.

Instead, we have postulated different scenarios that could be achieved for an individual through early intervention, ranging from a small improvement in quality of life only, through to improved outcomes in a number of areas. If a benefit is reflected in a particular scenario it means that there has been a positive change in an outcome as a consequence of early intervention. The way we have captured this was outlined in the table above.

We cannot estimate BCRs for each disability. This is because we do not have an adequate evidence base to be able to do so. Further, with the exception of visual impairment (where we have not been able to obtain any reliable estimates of the costs of early intervention), we have only sourced early intervention costs from one service provider in each disability category. While these estimates are considered a reasonable

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2 It is important to recognise that if a change is not assumed to occur under a particular scenario, it does not mean that the ‘base case’ scenario is an adverse outcome. For example, if a scenario does not assume any change to employment outcomes, this simply means that there is no change in that outcome. It does not imply that the person would otherwise have been employed or unemployed. This focus on changes that are the direct consequence of intervention is fundamental to an incremental analysis.
indications of the costs incurred, we recognise that different programs may involve
different costs.

We have not been asked to assess the efficacy of the intervention model that each of
those service providers delivers or how they compare against other models. For
example, our estimate for autism is based on an intensive, integrated 35 hour week
program delivered in a specialised centre. If we presented BCRs for autism based on
the costs of this program, it could also be assumed that these same BCRs apply to other
programs that could employ very different treatment models – even if the costs of
those other programs were not dissimilar.

Accordingly, in not being able to estimate BCRs for different disabilities this does mask
the actual underlying variability in benefits and costs, particularly for those disabilities
that are multi-dimensional in nature. The costs of different intervention programs
could also be expected to vary considerably and the BCRs will be sensitive to this. We
have therefore subjected the BCRs to sensitivity analysis for different program cost
estimates.

A large number of alternative scenarios could therefore be identified. We have
examined eight possible scenarios, which are listed below.

### Outcome scenarios for early intervention

<table>
<thead>
<tr>
<th>Scenario</th>
<th>Education</th>
<th>Employment</th>
<th>Living independence</th>
<th>Quality of life</th>
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<tbody>
<tr>
<td>A</td>
<td>Child who would have attended a special school with support. We have captured this benefit as saving 50% of the incremental cost of special education.</td>
<td>No change</td>
<td>No change</td>
<td>Disability weight reduces by 0.02. The quality of life benefit is captured by applying disability weight reduction to the value of a life year.</td>
</tr>
<tr>
<td>B</td>
<td>Child who would have attended a mainstream school with support. We have captured this benefit as saving 50% of the incremental cost of special education.</td>
<td>No change</td>
<td>Reduces informal care by 5 hours per week. As this is not captured under the opportunity cost method (as would not change carer’s employment status), we have estimated the benefit as 50% of the replacement cost value.</td>
<td>Disability weight reduces by 0.05. The quality of life benefit is captured by applying disability weight reduction to the value of a life year.</td>
</tr>
<tr>
<td>C</td>
<td>Child who would have attended a special school can attend a mainstream school with support. We have captured this benefit as saving 50% of the incremental cost of special education.</td>
<td>Person would have otherwise been unemployed and secures a part-time job at the minimum wage.</td>
<td>No change</td>
<td>Disability weight reduces by 0.05. The quality of life benefit is captured by applying disability weight reduction to the value of a life year.</td>
</tr>
<tr>
<td>D</td>
<td>No change</td>
<td>No change</td>
<td>Person who would have otherwise had to live in a supported</td>
<td>Disability weight reduces by 0.1. The quality of life benefit is captured by</td>
</tr>
<tr>
<td>Scenario</td>
<td>Education</td>
<td>Employment</td>
<td>Living independence</td>
<td>Quality of life</td>
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<tr>
<td>E</td>
<td>No change</td>
<td>Person would have otherwise been unemployed and secures a part-time job at the average wage.</td>
<td>Reduced reliance on informal carer by 15 hours per week. We have estimated this by taking the average of the replacement cost value and the opportunity cost value (assuming the carer is able to secure part time employment as a result of the reduction in care).</td>
<td>Disability weight reduces by 0.1. The quality of life benefit is captured by applying that disability weight reduction to the value of a life year.</td>
</tr>
<tr>
<td>F</td>
<td>Child who would have attended a special school can attend a mainstream school without support.</td>
<td>Person would have otherwise been unemployed and secures a full-time job at the average wage.</td>
<td>No change</td>
<td>Disability weight reduces by 0.1. The quality of life benefit is captured by applying that disability weight reduction to the value of a life year.</td>
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<tr>
<td>G</td>
<td>Child who would have attended a special school can attend a mainstream school without support.</td>
<td>No change</td>
<td>Reduced reliance on informal carer by 15 hours per week. We have estimated this by taking the average of the replacement cost value and the opportunity cost value (assuming the carer is able to secure part time employment as a result of the reduction in care).</td>
<td>Disability weight reduces by 0.1. The quality of life benefit is captured by applying that disability weight reduction to the value of a life year.</td>
</tr>
<tr>
<td>H</td>
<td>Child who would have attended a mainstream school with support can attend a mainstream school without support. We have captured this benefit as saving 50% of the incremental cost of special education.</td>
<td>Person would have been only able to secure a part-time job at the minimum wage and secures a full-time job at that wage.</td>
<td>No change</td>
<td>Disability weight reduces by 0.1. The quality of life benefit is captured by applying that disability weight reduction to the value of a life year.</td>
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</table>

It is important to re-emphasise that these are hypothesised scenarios. The scenarios are not linked to a specific evidence base because sufficient evidence is not currently available. Instead, our analysis shows what these benefits might look like if certain improvements were achieved as a consequence of early intervention.

Our measurement timeframes are conservative. For example, employment benefits are estimated over a maximum 35 year working life, which is the average, not maximum, working life for a person in Australia. We have also only measured quality of life benefits over 20 and 40 years of adult life (that is, from 20 years of age).³ These

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³ We have also postulated uniform outcomes in terms of changes in the disability weight. It is important to consider these changes in the context of the average disability weight for each disability. For example, a reduction in the
measurement timeframes are not based on average lifespans – the decision to measure benefits over these limited timeframes is more likely to result in benefits being understated rather than overstated. Given the absence of a robust evidence base for these benefits (and their persistence through time), as well as some of the measurement issues that are discussed in more detail in this report, we consider that taking such a conservative approach is appropriate.

This does not mean that these benefits may not persist for longer timeframes. It does also not mean that improvements in quality of life for a child or adolescent do not have significant value.

**Results**

The total costs of early intervention programs vary across our disability categories, with different service providers quoting estimates ranging from around $55,000 per child to several hundred thousand (most were below $100,000). We have assumed a ‘base case’ total cost of early intervention of $80,000. As outlined below, we have also tested the sensitivity of our results to changes in this assumption, being total program costs of $60,000 and $100,000. Information regarding the indicative costs of different programs is provided in the report.

With the exception of reduced education costs, which are measured over the years of schooling, results are presented assuming that the benefits are maintained over 20 and 40 years of adult life (employment benefits are truncated at 35 years of working life). Our ‘base case’ discount rate\(^4\) is 3%, but we have also estimated the results using a 6% discount rate.

The rationale for our conservative assumption of limiting the timespan for measuring benefits in adult life was outlined above. To reiterate, it is recognised that some benefits may persist over longer timespans. It certainly does not reflect any assumptions regarding the lifespan of a person with a disability.

The following tables present the BCRs for early intervention program costs of $80,000, $60,000 and $100,000. As outlined above, in each scenario if the BCR is greater than one, the benefits exceed the costs.

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\(^4\) A discount rate is used to convert future values to today’s dollars, in order to reflect the time value of money.
### BCRs of early intervention: EI program cost per child = $80,000

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<tr>
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<th>A</th>
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<tr>
<td><strong>20 years</strong></td>
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<td>3%</td>
<td>2.0</td>
<td>4.4</td>
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<td>14.7</td>
<td>16.7</td>
<td>17.1</td>
<td>12.4</td>
<td>8.5</td>
<td>11.8</td>
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<tr>
<td>6%</td>
<td>1.6</td>
<td>3.5</td>
<td>7.3</td>
<td>11.4</td>
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<td>13.4</td>
<td>9.7</td>
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<td><strong>40 years</strong></td>
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<tr>
<td>3%</td>
<td>2.6</td>
<td>6.3</td>
<td>13.4</td>
<td>22.9</td>
<td>25.3</td>
<td>24.5</td>
<td>18.3</td>
<td>12.4</td>
<td>15.4</td>
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<tr>
<td>6%</td>
<td>1.9</td>
<td>4.7</td>
<td>9.1</td>
<td>14.9</td>
<td>16.7</td>
<td>16.7</td>
<td>12.3</td>
<td>8.3</td>
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### BCRs of early intervention: EI program cost per child = $60,000

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<th>A</th>
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<td>3%</td>
<td>2.7</td>
<td>5.9</td>
<td>12.5</td>
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<td>6%</td>
<td>2.2</td>
<td>4.6</td>
<td>9.7</td>
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<td><strong>40 years</strong></td>
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<tr>
<td>3%</td>
<td>3.5</td>
<td>8.4</td>
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### BCRs of early intervention: EI program cost per child = $100,000

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<td>3%</td>
<td>1.6</td>
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<tr>
<td>6%</td>
<td>1.3</td>
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<td><strong>40 years</strong></td>
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<td>6%</td>
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<td>13.3</td>
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<td>9.4</td>
</tr>
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</table>
These results show the potential for the benefits to materially outweigh the costs. This is shown in the following figure, taking selected scenarios as an example. The definitions of each scenario are provided in the table “Outcome Scenarios for Early Intervention” provided above.

**Costs of early intervention and benefits under selected scenarios**

We would caution against ‘ranking’ outcomes. Apart from the fact that this could be seen to suggest that certain improvements are more important than others, as highlighted above, it is difficult to make generalisations across different outcomes as they will ultimately depend on each person’s starting point/potential, or the ‘base case’ scenario without intervention, which is impacted by the nature and severity of their primary and associated condition/s.

As we have also indicated, a number of the outcomes are linked. For example, enabling a person who would have otherwise been unemployed to gain a job could have significant productivity benefits. Employment outcomes will be linked to the person’s level of educational attainment, but will also be influenced by other external factors that cannot be directly controlled, such as socio-economic factors, employment opportunities in the person’s local area, and the attitudes of employers regarding employing people with a disability.
Interpretation

In the field of economics, BCRs of the magnitude observed above are substantial. Indeed, even if early intervention yields only a relatively small improvement in quality of life (Scenario A), the benefits still outweigh the costs. As outlined above, we have sought to make this analysis conservative. Apart from the assumptions noted previously, we would reiterate that it does not include costs such as improvement in the quality of life for families, which evidence suggests is a significant and material benefit of early intervention.

We must also reiterate that these are possible outcomes for a child. We have no data to assign any probabilities to the outcomes proposed above, or to extrapolate estimates across the entire population of people with a disability in Australia.

Most importantly, there is significant variability underpinning these outcomes, both between and within different types of disability. Not all children will benefit from early intervention, but some may achieve outcomes in excess of the estimates proposed. Some of this uncertainty will reduce as we progress further through the current generation of early intervention research.

Outcomes for children with visual and hearing impairment (without other comorbid conditions) may be more stable and predictable compared to the other disabilities. In particular, the evidence we have presented for hearing impairment, when managed with Auditory Verbal Therapy following cochlear implant, suggests a greater likelihood that any positive changes from early intervention will persist well into adult life. Achieving stable and predictable outcomes is more challenging for multi-dimensional conditions given intervention strategies need to address a number of different impairments, however gains in one or more of these areas can still be achieved.

Conclusions and implications

There is a strong foundation of evidence in support of early intervention as an overarching management approach that generates significant benefits for children with

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5 It is also important to note that for these two disabilities, the baseline outcomes without early intervention will be higher than the baseline outcomes for the other disabilities (particularly for those with severe impairments). For example, a person with a hearing impairment who has a hearing device but received no intervention is still more likely to be able to get a job, although they may be underemployed. In this case, early intervention has the clear potential to enable that person to maximise their full potential, and perhaps secure a job that reflects the full extent of their skills and capabilities. This would have a significant impact on that individual but also benefits the wider economy.
disabilities and their families. The potential for early intervention to produce benefits no longer appears to be in dispute.

The purpose of this review is to review the economic benefits (and costs) of early intervention for children with disabilities. The focus of our review is on two discrete conditions, Hearing Impairment and Visual Impairment, and three comparatively multi-dimensional conditions, ASD, Cerebral Palsy and Down Syndrome.

Overall, there is currently insufficient evidence of the long-term benefits of early intervention strategies for each disability to enable us to robustly estimate the economic benefits strategies employed for specific disabilities. Accordingly, we have hypothesised the types of benefits that could be achieved for a child with a disability (based on a number of different scenarios) and estimated what the BCR would be depending on the cost the early intervention program. This analysis is considered a starting point in terms of framing a potential assessment methodology as well as showing that early intervention does have the potential to generate economic benefits that significantly exceed the costs.

All population groups will benefit from further research to determine which EI strategies work best for children with each condition, during which critical ‘window of opportunity’ to improve a child’s development and functioning, and why. Longer term outcomes studies should also be part of this agenda.

Minimising decline in functional capacity following birth is another area where research is required, though there are ethical dilemmas with randomising intervention in these situations. Finally, research must aim to develop best practice services that meet the specific needs of each child and their family. This will assist in optimising outcomes for the child as well as the wider community.

Many children will also need ongoing support - some well into their adult life - however that does not mean that early intervention is still not an essential foundation for providing that child with the best opportunity possible to realise their full potential. Depending on the nature of the disability, improvements can vary significantly from the individual being able to perform a specific daily living skill with no or minimal assistance, through to being able to improve employment outcomes and live more independently.

The results we have presented here are indicative estimates that could be achieved for a child, noting that outcomes will vary considerably between children and for different disabilities. The approach that we have taken reflects the absence of robust data that is available linking specific intervention strategies to long-term outcomes. While the need
for such research remains important, it is also very challenging to implement and reasonable expectations need to be set in this regard.

This report should be considered a starting point as part of the journey to understand the economic benefits and costs of early intervention. It is also important to recognise that our approach focuses on the economics of early intervention. This is only one aspect of the rationale for early intervention. There are other more significant considerations, such as the rights of the child (and the family) to be able to maximise their full potential.
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Glossary of economic terms

Benefit Cost Ratio is the relationship between the net present value of the benefits and costs associated with an investment or policy. A BCR of greater than 1 means that the benefits exceed the costs.

Contingent Valuation Method is a non-market based method that attributes values to non-market goods and services based on individuals’ willingness to pay or accept, which are inferred from their preferences for the goods or services.

Discount rate is used in a cash flow analysis to determine the present value of benefits and costs which are to be incurred in the future. The discount rate takes into account the time value of money and any risks associated with forward-looking cash flows. In cost-benefit analysis, the use of a discount rate enables policy makers to compare cash flows across different time horizons.

Incremental cost refers to the cost that is incurred as a result of the implementation of a new or changed policy or measure. This does not include the costs that are incurred in the absence of the new or changed policy or measure. An incremental analysis of a policy focuses solely on the costs and benefits incurred in moving from the base case (without the policy) to the changed state (with the policy).

Net Present Value is the difference between the present value of the future cash flows associated with an investment or government policy and the present value of the total costs incurred in undertaking the investment or implementing the policy. The present value of future cash flows is determined by applying a discount rate (see definition above).

Opportunity cost is the value of the next best alternative that must be foregone in undertaking a particular activity (e.g. informal care). The opportunity cost method values informal care by estimating the loss in value associated with the time that the carer dedicates to informal caring.

Replacement cost involves substituting a value to obtain an estimate for the cost associated with an activity. The replacement cost method values informal care by applying an imputed hourly market rate to the number of hours dedicated to informal care services. This rate is intended to reflect the value of one hour of the carer’s time.

Total Economic Value is the sum of all values or benefits associated with an investment, policy measure, good or service. This includes all market and non-market values and all use and non-use values.
Transfers occur where economic welfare shifts between members of society (e.g. taxes). These transactions do not represent costs or benefits but simply shifts in existing resources and should therefore not be taken into account when conducting a social cost-benefit analysis.

Underemployment occurs where an individual is employed, however not to the desired extent. Underemployment can relate to compensation, number of hours worked, skill level or the capacity (activity) in which the individual is employed.
1 Introduction

Synergies Economic Consulting (Synergies) has been asked to prepare a report for the Not for Profit Children’s Lobby Group on the economic benefits of early intervention for children with disabilities.

As part of this review we have been asked to focus on five specific disabilities, being:

- Autism Spectrum Disorder
- Cerebral Palsy
- Down syndrome
- Hearing impairment
- Visual impairment.

The review examines the specific nature of each of these disabilities and how early intervention has the potential to benefit children that are diagnosed with them. While it is not intended to comprehensively cover all disability types, in representing some of the more common disabilities affecting children in Australia this review will inform a general assessment of the potential role of early intervention in the lives of children and their families.

The Productivity Commission’s Final Report on Disability Care and Support recommends the building of an evidence base for early intervention strategies, as well as undertaking economic analysis such as cost-benefit analysis. It also recognised the issues in developing a robust evidence base for early intervention, in particular, longitudinal studies that track outcomes for children who have received early intervention into their adult life.

As will be discussed in this report, the early intervention research that has been conducted to date has established that it has the potential to generate significant benefits for children with disabilities and their families. However, not all strategies work effectively for all children under all circumstances. The current and future research is more targeted. It will add to the existing evidence base by enabling us to understand which strategies work best for whom, under what circumstances, and why. Longer term outcome studies should also be part of this agenda.

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In this report we will examine some of the more recent evidence available on early intervention strategies for each disability. We will then examine how the benefits can be measured. Benefit Cost Ratios (BCRs) will be estimated based on indicative costs of early intervention.

Given the very limited amount of outcomes data evaluating the long-term effectiveness of specific intervention strategies across the five disability types we have examined, our analysis of the benefits and has been limited to considering a number of plausible outcome scenarios for a child with a disability who receives early intervention. Given the inherent difficulties in estimating these benefits and the uncertainties in relation to some of the longer term outcomes, we have sought to take a conservative approach (that is, an approach that is more likely to under-estimate the benefits than over-estimate them).

This report should be considered a starting point as part of the journey to understand the economic benefits and costs of early intervention. It is also important to recognise that our approach focuses on the economics of early intervention. This is only one aspect of the rationale for early intervention. There are other more significant considerations, such as the rights of the child (and the family) to be able to maximise their full potential.

The report is structured as follows:

- section 2 provides an overview of early intervention and outcomes that are known from available research;
- section 3 describes the methodology used to estimate the benefits in this report;
- sections 4 to 8 discuss the potential benefits of early intervention for each of the five disabilities;
- section 9 estimates BCRs based on a number of hypothesised outcomes scenarios; and
- section 10 concludes the report.

Summaries of our review of the literature on early intervention for each of the five disabilities are contained in the Appendices.
2 Overview

2.1 Early intervention: what is currently known

Early intervention is an umbrella term that is used by various service providers to represent a heterogeneous range, combination and intensity of services and treatments employed to meet the needs of individual children with a range of primary conditions and associated problems and their families. Therefore, there is no blanket early intervention strategy that is either effective or appropriate for all children under all circumstances.

2.1.1 Goals of early intervention

As will become evident from this report, early intervention can be delivered in a number of different ways, depending on the nature of the child’s impairment/s, as well as the family and community environment in which the child lives. The goals of early intervention can also vary, for example:

EI is both an intervention program that can remediate the extent of impairment or lessen future difficulties, or do both for children with moderate and relatively severe disabilities identified early in life. EI also helps these children acquire compensatory skills for typical functions they will never acquire because of a disability... For children with mild developmental problems or risk conditions, high-quality EI programs can prevent the development of poor functioning later in life that may be associated with early developmental problems or risk conditions. Given the variability of children served in EI, we would expect different kinds of long-term outcomes for different types of children.

In 2011, the Productivity Commission defined the goal of early intervention as follows:

In general, the overarching objective of early intervention is to incur expenditure on a particular intervention today that, not only improves individual outcomes beyond that which would occur in the absence of the intervention, but lowers the costs and impacts associated with the disability for individuals and the wider community over the longer-term... More fundamentally, early intervention seeks to reduce the impact of disability for individuals and the wider community — for example, by:

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- mitigating or alleviating the impact of a newly acquired, newly diagnosed or an existing disability, and/or
- preventing a deterioration in an existing disability.

This report will examine different intervention practices, as well as what is currently known about the general principles underpinning good intervention practice, however it will not seek to evaluate or compare specific intervention strategies. In examining different intervention practices our report does not intend to be comprehensive – instead, our aim is to provide an overview of some of the approaches that are currently applied.

As will become evident from this review, early intervention is not simply advocated for its own sake – it does need to be appropriately targeted to the needs of the child and the family. Not all strategies will be effective for all children, and the family environment and other circumstances can also have a significant impact on the outcomes that are realised. The quality of the service itself is also important.

Many children will also need ongoing support – some well into their adult life - however that does not mean that early intervention is still not an essential foundation for providing that child with the best opportunity possible to realise their full potential. Depending on the nature of the disability, improvements can vary significantly from the individual being able to perform a specific daily living skill with no or minimal assistance, through to being able to gain employment and live completely independently.

What this report will demonstrate is that there is a strong and continually growing foundation of knowledge and evidence regarding early intervention. Examples of some of this evidence are provided in the Appendices. This overview is not a comprehensive review of early intervention literature nor does it address its potential effectiveness across all functional domains.

2.1.2 Evolution of early intervention research and practice

There has been significant advances in early intervention research and practice in recent decades. In particular, advances continue to be made in understanding the underlying science. We now know considerably more about early development and hence why early intervention has the potential to positively influence outcomes for children with disabilities and their families.

There has also been a change in the way we view disability. The biopsychosocial approach considers health and disability within a broader context, considering biological, psychological and social factors and the interactions between them.
In 2001, the World Health Assembly endorsed the International Classification of Functioning, Disability and Health (ICF), which is based on this biopsychosocial model. It classifies health-related domains from a body, individual and societal perspective by way of:

- a list of body functions and structure
- a list of domains by activity and participation.\(^9\)

It also considers environmental factors, including: products and technology, the natural environment (and human-made changes to the environment), support and relationships, attitudes and services, systems and policies. The World Health Organisation (WHO) describes the ICF as putting the experience of disability in the ‘mainstream’, recognising that it could occur in any individual to some degree and is accordingly a “universal human experience”.\(^10\)

The provision of early intervention that targets specific improvements in a child’s development (including their acquisition of specific skills and behaviours) is of fundamental importance. However, intervention strategies also need to consider the context of the environment (which is discussed further below).

Bailey et al summarise modern early intervention theory as being grounded in two main sets of assumptions.\(^11\) The first set of assumptions include neurobiological development, critical and sensitive periods, attachment theory, infant learning paradigms, prevention theory, intervention research and the quality of change occurring in the early years of life. That is, early years present an opportunity to have a significant impact and accordingly, the key issue for early intervention is how we make the most of this plasticity.

The second set of assumptions are based on the environment, including family systems theory, stress and coping, ecological perspectives on development, the role parents play in shaping child’s development, cultural influences and collective experiences shared by parents of children with disabilities. That is, early identification of disabilities in a child has profound implications for families and requires special effort to assure support. In particular, the family environment will have a significant

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influence on learning and development and the success of any early intervention strategy. Bailey et al state:12

Most current conceptualisations recognize that early intervention is not a discrete event but rather a complex series of interactions and transactions centred around the accomplishment of two basic tasks: nurturing and enhancing the development and behaviour of the infant or toddler with a disability, and supporting and sustaining their families. Within these two tasks, enormous variation occurs in the way these challenges are met.

A report commissioned by the Victorian Department of Education and Early Childhood Development identified a number of factors that children need to promote development. These factors are presented in the Box below.

Box 1  Key things a child needs to promote development

- close and ongoing caring relationships with parents or caregivers
- adults who recognise and are responsive to the particular child’s needs, feelings and interests
- adults who are able to help children understand and regulate their emotions
- adults who are able to help children understand their own mental states and those of others
- adults who are able to help children negotiate temporary breakdowns and ruptures in relationships
- protection from harms that children fear and from threats of which they may be unaware
- clear behavioural limits and expectations that are consistently and benignly maintained
- opportunities and support for children to learn new skills and capabilities that are within their reach
- opportunities for children to develop social skills through regular contact with a range of adults and other children
- opportunities and support for children to learn how to resolve conflict with others cooperatively
- stable and supportive communities that are accepting of a different families and cultures.

Source: Centre for Community Health, Murdoch Children’s Research Institute & The Royal Children’s Hospital, Melbourne (2010). DEECD Early Childhood Intervention Reform Project: Revised Literature Review, December, p.11.

In reality, development will ultimately depend on both early and subsequent opportunities and experiences. However, in the absence of effective early intervention, a critical ‘window of opportunity’ to improve a child’s development and functioning – or to at least minimise any subsequent decline in the capacity they already have at birth – will be lost. This also highlights the importance of early identification to ensure that services can be accessed at the right time.13

2.1.3 What is known about the actual and potential impacts of early intervention

There are two main categories of studies that can be used to assess early intervention.14 Efficacy studies evaluate the extent to which certain strategies can work (or have the potential to work), based on what is known about developmental theory and intervention practices. Effectiveness studies assess the extent to which intervention does work based on actual studies of children who have received particular early intervention services. Given these studies test the actual effectiveness of specific intervention strategies in practice, they will be afforded considerably more weight than efficacy reviews, as the latter are not evidence-based and tend to reflect personal or expert opinion.

An overview of some of the more recent literature on efficacy and effectiveness for the five disabilities that are within the scope of our review is provided in the Appendices, focusing on effectiveness studies where possible. Our review is not intended to be comprehensive however it does show that there is an empirical foundation for the benefits of early intervention.

Ziviani et al undertook an extensive literature review of the effectiveness of early intervention programs for children with physical disabilities.15 This paper reviewed studies published in peer reviewed journals from 1990 to 2008, limiting the review to studies using a randomised control trial, quasi-randomised or non-randomised control trial, cohort or cross-sectional study design, where the effects on the child and/or the family were measured. After identifying 355 papers they arrived at a final sample size of ten, with the most common reason for exclusion being inappropriate research objectives.

The results of the studies showed that early intervention can lead to positive outcomes for children and their families, however “methodological limitations precluded more rigorous analysis of findings.”16 One issue identified was outcomes measurement, with few standardised measures evident. The authors conclude that few studies were of a high methodological quality however they also recognised the difficulties with this, primarily the ethical concerns with excluding children and families from intervention in randomised controlled trials.

There are of course some practical challenges in designing early intervention studies. Blackman observes:\(^{17}\)

Because early intervention as a concept has so many different dimensions, from the individual to the family to society, it is not surprising that well designed studies are challenging. Furthermore, randomized, controlled studies of sufficiently large numbers of subjects to allow statistical analysis of confounding variables and individual differences are expensive and unpopular since it would be difficult, perhaps unethical, to provide no intervention for a true control group.

This was also recognised by the Productivity Commission:\(^{18}\)

The most robust standard of evidence — a combination of a systematic review of randomised controlled trials on effectiveness and benefit-cost analysis — is likely to be the most costly and slow to obtain (apart from where there are already international studies).

Bailey et al propose:\(^{19}\)

Ultimately a large scale clinical trial to further answer the question of whether early intervention is effective or not may not be a reasonable expectation for the field, due to this incredible variation in child and family characteristics, potential treatment models, and the transactional nature of human interactions. What is likely to be more useful will be smaller, well-controlled, and carefully implemented studies that validate specific practices with children and families who have specific needs and want those services.

The other challenge for longitudinal studies is that at the time they are published, theories of development and early intervention may have moved on significantly, which may mean that some of the intervention strategies that have been examined are effectively out of date.

In order to be able to measure the long-term benefits of early intervention within a cost-benefit framework, we require robust studies (that is, studies with an appropriate methodological design) providing evidence of the extent to which early intervention influences long-term outcomes for the child (and their family). These long-term outcomes include educational achievements, employment, living independence and quality of life impacts.

\(^{17}\) Blackman, J. (2002). p.15.


Based on our review, this long-term outcomes evidence is currently not available. However, particularly given the strong foundation for early intervention that has already been built, it is clear that it has the potential to generate significant long-term benefits. It is expected that this evidence base will be augmented by long-term effectiveness studies in the future.

2.1.4 What is known about the impact of early intervention on families

There is also evidence showing the positive outcomes that can be achieved for families through early intervention.

As outlined above, the family environment plays a critical role in a child’s development and accordingly, family systems theory is part of the current set of assumptions underpinning early intervention practice. Further, having a child with a disability can introduce a number of stressors, from initially coming to terms with a child’s diagnosis and having to make decisions regarding supports that are needed through to the impact that it can have on family dynamics and other family members.

The report commissioned by the Victorian Department of Education and Early Childhood Development highlighted that families of children with disabilities have the same general needs as families with typically developing children but require additional support, as they face additional challenges that pose risks of poor outcomes for themselves and their children. It was noted that these families are at a greater risk of a number of social and psychological stresses, including health problems, family breakdown, poor housing and financial stress. Guralnick observes:

To be sure, many families adapt well to children with disabilities in their family, but recent evidence continues to suggest that it is not uncommon for parents to experience long-term difficulties even in resolving issues surrounding the diagnosis of a disability, a stressful circumstance that can affect important caregiving processes.

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20 One of the most widely referenced models is Bowen’s family systems theory (1966, 1978), which was one of the first comprehensive theories of how families function. His particular focus was on patterns that develop in families to diffuse anxiety. For a review, refer: Brown, J. (1999). Bowen Family Systems Theory and Practice: Illustration and Critique. The Australian and New Zealand Journal of Family Therapy. 20(2), pp. 94-103.

21 Centre for Community Health, Murdoch Children’s Research Institute & The Royal Children’s Hospital, Melbourne (2010).

22 Centre for Community Health, Murdoch Children’s Research Institute & The Royal Children’s Hospital, Melbourne (2010). pp. 20-21.

Given what is known about the impact of family systems theory, early intervention programs are capable of facilitating more optimal family interaction patterns or moderating the impact of stressors by providing resource supports, social supports and information.24

There are a number of published studies that have focussed on family outcomes. For example, Bailey et al (2005) examined 2,586 families who had participated in an early intervention program under Part C of the Individuals with Disabilities Education Act.25

The study reported positive outcomes in terms of supporting the family to help their child learn and develop, as well as helping them work with professionals and advocate for services for their child. Two-thirds of the sample rated their quality of life as excellent (38%) or very good (28%) and were feeling much more hopeful about the future. 59% said their family was much better off after early intervention, with 23% somewhat better off.

A 2007 study of 2,166 US families of children who had received early intervention services also reported very positive outcomes, although noted that these outcomes were influenced by a complex interplay of child, family, program and community variables.26 The quality of the services provided to the family was found to have a direct impact on the family (as well as the child), with this impact being largely beneficial and making them more optimistic about the future. It was also noted that informal support systems also played an important role in promoting optimism and providing parenting confidence.

An Australian study by Davis and Gavidia-Payne in 2009 noted that Family Quality of Life (FQOL) is emerging as a key outcome of services for children with disabilities, recognising the importance of the family in influencing child development.27 It was noted that early intervention programs can influence positive outcomes for children with disabilities by focussing on other aspects of the family system and improving FQOL.28

28 Another assessment tool that has been developed is the Measure of Processes of Care (MPOC), which enables parents to assess the extent to which services received are family centred. Refer: King, S., Rosenbaum, P., & King, G. (1995). The Measure of Processes of Care: A Means to Assess Family-Centred Behaviours of Health Care Providers. Hamilton, ON: McMaster University, Neurodevelopmental Clinical Research Unit.
The authors surveyed 64 families in the Melbourne area (16% responded). It was found that parental perceptions and experiences with family-centred professional support are associated with FQOL, and indeed professional support was found to be one of the strongest predictors of FQOL. The importance of a family centred approach to intervention was therefore highlighted.

2.1.5 What we know about early intervention practice

The significant advances that have been made in understanding development and early intervention theory mean that much is now known about what constitutes good intervention practice. Practice is now becoming more evidence-based, with this evidence used to address gaps in the research and identify what is known about certain interventions in order to understand how and when they work. Evidence-based practice has itself evolved from having a fairly narrow focus, to integrating the best research evidence with clinical expertise and patient values.29

That is, it is necessary to understand the key features of best practice service delivery (such as method, structure, environment and skills of staff) in order to deliver optimal outcomes and to also provide insights into what will work best for which children.30 We note that there is some tension in the literature regarding finding an appropriate balance between the strict and consistent application of evidence-based practice and local flexibility. For example, Odom observes that implementation science focuses on the process of delivering early intervention, enabling us to ‘unpack’ the model to determine which features will affect the desired outcomes.31 Practitioners will often adapt the model to fit their own context.

Guralnick posits a set of early intervention principles that in his opinion, appear to have achieved international consensus:32

1. a developmental framework informs all components of the early intervention system and centres on families

2. integration and coordination at all levels of the early intervention system are essential


30 Centre for Community Health, Murdoch Children’s Research Institute &The Royal Children’s Hospital, Melbourne (2010).


3. the inclusion and participation of children and families in typical community programs and activities are maximised
4. early detection and identification procedures are in place
5. surveillance and monitoring are an integral part of the system
6. all parts of the system are individualised
7. a strong evaluation and feedback process is evident
8. true partnerships with families cannot occur without sensitivity to cultural differences and an understanding of their developmental implications
9. recommendations to families and practices must be evidence based
10. a systems perspective is maintained, recognising interrelationships among all components.

In another paper, Guralnick responds to criticisms that have been raised in terms of the absence of robust evidence on the long-term benefits of early intervention (as will be evident from this report, most studies have a reasonably short-term focus).\(^{33}\) He states that understanding how early intervention produces these short-term outcomes is vital to understanding the long-term effects and the extent to which gains made in the short-term diminish over time:\(^{34}\)

...the negative findings are not nearly as consistent or pessimistic. What is needed is a framework that will guide our understanding of and establish reasonable expectations for both short- and long-term outcomes.

He observes that studies that have demonstrated longer term gains (and have been based on an appropriate scientific method) can be used to identify critical elements of the developmental framework. He highlights the intensity of the intervention (both information and services) as one such factor, with services often provided on a one-to-one basis, comprehensively involving the child, family and community. They are also intensive in terms of duration.

It was also highlighted that long-term effectiveness also depends on the continued existence of family stressors (in particular, those that worsen with time (e.g. children with significant physical impairment that require long term physical assistance from their parents, which produces increasing health risk to parents as the child grows) or


stressors that arise as a consequence of unanticipated problems (e.g. behavioural difficulties)). If they continue to interfere with family interaction patterns, extended interventions in some form may be necessary:  

This analysis suggests that intensity defined as the level of intervention occurring within a specified time interval (density), intensity defined as occurring across a longer period of time (duration), and possible intensity defined as containing more early intervention components (comprehensiveness) may well be essential for long-term effectiveness.

The notion of specificity is also seen as important, including a further understanding of the relationships between child and family factors, program factors defining interventions and desired outcomes. This will also help us understand how lower intensity early intervention programs can still result in sustained successes (for example, if certain stressors are not significant or are buffered by family characteristics, intervention may not need to be as intensive). Guralnick identifies this specificity problem as potentially “the central task for the second generation of research in the field of early intervention.”

2.2 Future directions for early intervention research

As outlined above, one of the criticisms of early intervention research is the absence of studies that focus on the long-term outcomes, that is, studies following a cohort of children who received a specific form of early intervention well into adulthood, with the long-term characteristics of the group referenced to their characteristics at entry level. Criticisms have also been made in terms of scientific method, for example, where studies do not include a randomly selected control group.

Guralnick identified specificity as the potential focus for the next generation of early intervention research. This includes understanding why outcomes can vary dramatically across children and their families. Bailey et al concur with this view:

Future research should shift away from the question of whether to intervene and instead to ask how, for whom, and to what end. This will require a clear specification of goals, careful description of intervention models, and an assessment of whether specified models are actually implemented. Longitudinal studies are also

needed to determine whether meaningful outcomes are attained in later life. However, it may be an unrealistic and unfair standard to expect early intervention to affect adolescent and adult outcomes of children with disabilities, given the range of intervening experiences that occur subsequent to the completion of early intervention efforts.

Access to appropriate ongoing support services following early intervention, including assistive technologies, could also impact these longer term outcomes.

Minimising decline in functional capacity following birth is another area where research is required, though there are ethical dilemmas with randomising intervention in these situations.

One priority identified by Bailey et al was determining the outcomes expected of early intervention for children and their families. A further priority is determining appropriate models and treatment intensity, including addressing the relative balance between child goals and supporting the family. Other priorities they identified include:

1. factoring service quality into the efficacy equation
2. accounting for child and family variables in determining efficacy
3. integrating findings from neuroscience and human genetics.

A paper by Ziviani et al noted that while the benefits of early intervention are widely known, the efficiency of the services is not widely documented. Program logic is an approach that can be used to evaluate this. The authors identified a number of issues with program evaluation studies that have been done in the past, including poor descriptions of program characteristics, a lack of documentation on implementation processes, and a lack of information on whether success is driven by the intervention, implementation or both. It was also noted that when evaluating programs, it is important to understand the way in which the service provider interprets policy goals, as well as the impact of differences in contextual factors.

The fact that early intervention can generate significant benefits for children with disabilities would no longer appear to be in dispute. However, much needs to be known about what strategies work for whom and in what environments. It is also a reality that many children will continue to require services and supports, including

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assistive technology strategies - some well into their adult life. In addition to the priority areas identified above, long-term follow-up studies (of appropriate quality) could greatly contribute to this knowledge and will continue to be a priority to add to the growing body of early intervention research.

2.3 The rationale for early intervention

The Victorian Department of Education and Early Childhood Development’s Early Childhood Intervention Reform Project summarised a number of significant and important reasons for early intervention. The first is the development rationale, with research evidence on child development showing that early intervention can be an essential foundation for improving outcomes and/or preventing further declines in functioning. Further, based on our understanding of how skills are acquired, early intervention is much more likely to be effective than attempting to address these issues later in life. For families, the earlier intervention occurs, the easier it will be for them to adapt to the additional challenges presented by their child’s disability, which will benefit both the child and the family.

The empirical rationale, which was introduced above and will be further explored in this report, shows that there is a growing body of evidence that demonstrates the actual and potential ability of early intervention to yield significant improvements in functioning and quality of life.

A fundamental rationale for early intervention is recognition of the rights of the child and the family. The United Nations Convention on the Rights of a Child (1989) comprises 54 articles, including recognising that:

...all children have the right to participate fully in and to benefit from educational experiences and play a full part in society.

As outlined previously, the interpretation of what is regarded as playing a “full part in society” varies significantly across a spectrum depending on the nature of the child’s impairment, as well as the influence of other environmental factors. In some cases, for example, the provision of Auditory-Verbal Therapy (AVT) for a child with hearing loss that receives a cochlear implant, the person may be able to secure a full time job and live independently to the extent that it is not even evident that the person has a hearing impairment. In other cases, participation in early intervention may improve one or

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41 Centre for Community Health, Murdoch Children’s Research Institute & The Royal Children’s Hospital, Melbourne (2010).

42 Centre for Community Health, Murdoch Children’s Research Institute & The Royal Children’s Hospital, Melbourne (2010). p.12.
more daily living skills. While some people may not achieve full living independence or be able to secure paid employment, this could still materially improve quality of life for the individual and their families.

The focus of this report is on the economic rationale for early intervention. To the extent that early intervention can generate the types of improvements summarised above (and explored further for each of the five disability types), investment in early intervention and support can generate significant financial and economic benefits for society by avoiding or reducing other costs that will otherwise be incurred later in that child’s life as well as the direct welfare gains associated with improved employment prospects. The avoided or reduced ‘costs’ include not only direct costs, for example expenditure on formal care services, but indirect costs such as a reduction in quality of life and the impact on informal caregivers.

Cunha and Heckman show that “preferences and skills determined early in life explain a substantial part of lifetime inequality.” They cite a US study that showed that 50% of lifetime inequality in the present value of earnings is determined by factors known by age 18. The weight of evidence shows that both cognitive and non-cognitive abilities are important predictors of lifetime outcomes, which highlights the importance of early investment.

The economic and financial benefits are not only about the impact on the individual. Importantly, these benefits also accrue to the family and wider community. This report will seek to explore these potential economic benefits and how they can be quantified, and will compare them to the typical costs of an early intervention program.

While there are challenges in robustly quantifying these benefits, it provides a starting point that can be further built upon as more robust evidence on lifetime outcomes is gathered. This in turn provides important information to service providers and Government in allocating funding for services. It also responds to the Productivity Commission’s Final Report on Disability Care and Support, which amongst other things, recommends the building of an evidence base for early intervention strategies, as well as undertaking economic analysis such as cost-benefit analysis.

Importantly, this report is not proposing that the economic rationale is the only justification for early intervention, nor should it necessarily be considered the most important one. This economic rationale needs to be considered within the wider context, including the rights of the child and the family.

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3 Methodology

3.1 Overview of the cost-benefit approach

This report will separately examine the potential costs and benefits of early intervention for each of the five disabilities that have been included in the scope of our review. All estimates have been done on a per person basis. We have not sought to develop population estimates of the costs and benefits as among other things, it would require robust data on the following:

1. the number of children with the disability that are enrolled in early intervention programs in each year;
2. the types of early intervention received; and, most importantly
3. the range of outcomes that are likely to be experienced across that group of children, reflecting the differences in the nature of the impairments as well as the effectiveness of specific intervention strategies.

Robust population data in all three of the above areas – particularly the third - for children with disabilities in Australia is currently not available for all of our disability categories, nor can we estimate them with an appropriate degree of reliability.

We have therefore sought to estimate the potential benefits that could be generated for a child who undergoes early intervention, relative to the total costs of a child accessing the program. For an investment to be ‘net present value positive’, the benefits need to exceed the costs (and not by any threshold order of magnitude). A common measure that is used is the BCR. If the ratio of benefits to costs is greater than one, the investment will yield positive economic benefits.

In our view, the most important thing to demonstrate at this stage is the likelihood that the benefits of early intervention will exceed the upfront costs of early intervention, recognising that in many cases, the actual outcomes could vary across a spectrum (and will also be influenced by other factors, such as comorbid conditions). This is particularly the case for multidimensional conditions such as ASD, Down Syndrome and Cerebral Palsy. Outcomes can also vary across an individual’s lifespan.

In essence, the benefits are the reduced or avoided future costs associated with a particular disability and increased economic output resulting from the improvement in productivity of the individual (and potentially their caregiver). Accordingly, the starting point for establishing the benefits of early intervention is the potential lifetime trajectory for a person with the particular disability who has not received any early intervention. These outcomes have also been quantified across populations in ‘cost of
illness’ studies. While these studies can paint a very negative picture, they do provide an understanding of where and how the impacts arise and highlight why appropriate services and supports are so important and where they are needed.

We are not intending to focus on those lifetime outcomes in detail here. Instead, we will focus on how early intervention could potentially alter these outcomes in a number of areas. Most fundamentally, early intervention improves a child’s learning and development and potentially their cognitive ability, physical functioning, motor skills, communication, social skills and behaviour. Ultimately, these improvements translate into lifetime outcomes such as living independence, employment and quality of life.

The analysis cannot simply assume that all benefits could be realised for all children under early intervention. For each disability we will refer to the more recent evidence that is available that supports the extent to which a particular outcome could be achieved as a consequence of early intervention. Where possible we have relied on effectiveness studies (that is, studies that have assessed actual outcomes) however this is also supplemented by efficacy studies (that is, studies that have examined the potential for a particular strategy to yield positive benefits). Even where the evidence base is strong, the gains will vary between children and some may still exhibit little if any developmental progress.

As outlined previously, in the longer term as more robust Australian outcomes data becomes available, the measurement of these benefits should be able to be refined further and potentially extrapolated across the population.

The key areas we will focus on that can potentially be quantified are as follows:

1. employment
2. living independence
3. education
4. healthcare
5. quality of life.

The approaches are somewhat limiting however this reflects limited data availability (as will be discussed further below).

As outlined above, early intervention can also have a significant impact on families. We have not been able to quantify this impact but it should still be recognised as an essential consideration in evaluating the benefits of early intervention.
An overview of our approach to quantifying each of the above benefits is summarised below.

3.2 Education

Some children with a disability will need to attend special education. As at 2010, there were 332 Government special schools in Australia and 84 non-Government special schools.45

As education costs will be incurred for all children it is only relevant to focus on the incremental costs of special education (that is, the additional costs over and above the average costs of educating a child in a mainstream setting).

The 2011/12 Queensland State Budget provides estimates of the average costs of service per student in 2010-11.46 The average cost of primary and secondary education was $11,513. The average cost of service to students with disabilities was $26,881. The additional cost of providing education to students with disabilities was therefore $15,367 per student.

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.47 The cited costs are for the provision of special education services, although it is not specifically known as to what services are included in the estimate or how the average cost has been calculated.

These services can be provided in a special school environment or via the provision of specialised supports in a mainstream school. It is recognised that the actual costs for each child will vary depending on the school attended and the level of support required by each child.

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3.3 Employment

3.3.1 Potential benefits of early intervention for employment outcomes

To the extent that early intervention can improve the educational outcomes for a child with a disability, including not only academic performance but also in other areas such as social skills, physical skills and mobility, communication and behaviour, this in turn could improve the eventual employment outcomes for that child once they reach adulthood. These improved outcomes can manifest in a number of ways, including:

- a reduction in unemployment, that is, an individual that would not otherwise secure employment is able to get a part-time or full-time job;
- a reduction in underemployment, that is, an individual is able to get a job that makes the most of their skills and abilities; and
- there is an increase in productivity, where a person may be employed but has difficulty being fully productive at work.\(^\text{48}\)

The benefits of reducing unemployment can be measured as the contribution this makes to productivity, based on average weekly earnings measures (this is also termed the ‘human capital approach’). It also increases the taxation revenue raised by Government and reduces reliance on unemployment benefits, however these effects are ‘transfer’ effects rather than a net benefit. Accordingly, these benefits are not included as to do so would result in double-counting.

The benefits of reducing underemployment or increasing productivity are more difficult to quantify, although estimates can be made. For example, in the case of underemployment, we could measure benefits where:

- a person is able to secure full-time work when they would only have been able to get part-time work (based on the difference between full-time and part-time earnings); or
- a person is able to earn the average wage instead of the minimum wage.

The difficulty is establishing the extent to which underemployment currently exists. While there is data on employment outcomes for a number of the disabilities, data on underemployment and reduced productivity is not readily available. It is also important to note that some of these issues are independent of the individual. For example, unemployment or underemployment could reflect the attitudes of employers.

\(^{48}\) In the field of labour economics this is also sometimes referred to as ‘presenteeism’.
towards employing a person with a disability, rather than the capability of that person. Productivity issues could also arise where the person’s capabilities are not appropriately matched to the requirements of the position.

3.3.2 Estimates

As outlined above, we are limiting our estimates of the benefits of improvements in employment to productivity gains. As at May 2011, average weekly earnings were as follows:\textsuperscript{49}

- all employees: $1,020
- males: $1,251
- females: $800.

This represents an average annual salary of:

- all employees: $53,040
- males: $65,052
- females: $41,600.

Based on these assumptions, an estimated lifetime value can also be calculated, assuming:

- an average working life of 35 years, which has been used by the Review Panel examining reforms to the Australian tax system;\textsuperscript{50} and
- a discount rate of 3%, which has been used by the Australian Institute of Health and Welfare.\textsuperscript{51}

The present values of the lifetime benefits are:

- all employees: $1.14 million
- males: $1.398 million
- females: $0.894 million.


Even if an individual only gained full-time employment at the minimum wage ($589.30 per week\textsuperscript{52}), this still equates to $30,644 in a year or $0.658 million over a 35 year working life. We can also estimate outcomes for part-time work as some percentage of full-time. We have generally assumed 25 hours per week for part-time work, which is 62.5\% of a 40 hour week.\textsuperscript{53} We recognise that the actual part-time hours worked could be more or less than this. Sensitivity analysis can be used to examine the impacts of different working hours and working life spans.

There are a number of limitations of the human capital approach, which are largely based around its assumptions. The underlying assumption of this approach is a rigorous, fully employed economy where any additional resource earns their opportunity cost. 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, as well as the likely variation in outcomes between individuals with disabilities.

However, there are other potential benefits that have not been included here, such as a reduction in some or all of the social costs that can be associated with unemployment. These costs can include poverty, poor health, premature mortality, psychological stress, criminal behaviour, loss of human capital and family breakdown.\textsuperscript{54}

3.4 Living independence

People with a disability may need to rely on others to help them with daily living, ranging from basic skills such as bathing and toileting (for example), through to assistance in managing finances etc. The following chart summarises the types of support needed by users of services funded under the Commonwealth State/Territory Disability Agreement (CSTDA) and the National Disability Agreement in 2008-09. The types of activities covered, which are consistent with the ICF classifications, include:

- activities of daily living – self-care, mobility and communication;


\textsuperscript{53} Part-time work is defined by the ABS as anything less than 35 hours per week. The basis of this assumption is that the average part-time wage is 62.5\% of the full-time wage. It therefore assumes that the average hourly rate for a full-time employee is the same as part-time. Refer: Australian Bureau of Statistics (2011). Average Weekly Earnings Australia, May 2011, Catalogue 6302.0.

• activities of independent living – interpersonal interactions and relationships, learning, applying knowledge and general tasks and demands, domestic life; and

• activities of work, education and community living – education, community (civic), economic life and work.

Figure 1 Users of disability support services – need for support in life areas, 2008-09

This shows that the majority of service users are either always unable to do, or sometimes unable to do, activities in key life areas.

3.4.1 Estimating the costs of formal service use

It is possible to estimate the average cost per person of reliance on formal disability support services for each disability category. To the extent that early intervention increases the ability of a person to function in one or more of these key life areas, some of these costs will be avoided or reduced.

The Australian Institute of Health and Welfare (AIHW) publishes information on the utilisation of disability support services funded under the National Disability Agreement (this will not cover all expenditure on services by people with disabilities). The total expenditure on services and the number of people accessing them in 2009-10
is presented in Table 1. From this data we have estimated the average expenditure on each service type per person.

Table 1  Use of, and expenditure on, disability support services in the 2009-10 financial year

<table>
<thead>
<tr>
<th>Service type</th>
<th>Total number of users (2009-10 financial year)</th>
<th>Total expenditure per year (2009-10 $m)</th>
<th>Average expenditure per person (2009-10$)</th>
<th>Average expenditure per person per year as at June 2011$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accommodation support</td>
<td>39,854</td>
<td>2,581.3</td>
<td>64,769</td>
<td>67,101</td>
</tr>
<tr>
<td>Community support</td>
<td>127,909</td>
<td>832.2</td>
<td>6,506</td>
<td>6,740</td>
</tr>
<tr>
<td>Community access</td>
<td>58,632</td>
<td>646.8</td>
<td>11,032</td>
<td>11,429</td>
</tr>
<tr>
<td>Respite</td>
<td>35,978</td>
<td>345.1</td>
<td>9,592</td>
<td>9,937</td>
</tr>
<tr>
<td>Employment</td>
<td>118,801</td>
<td>627.1</td>
<td>5,279</td>
<td>5,469</td>
</tr>
</tbody>
</table>


This shows that the provision of support services is costly. In particular, accommodation support services cost an average of $64,769 per person in 2009-10 (or $67,101 in June 2011 dollars).

While the nature and frequency of service use will vary, it is likely that they will be accessed by a person with any one of the five disabilities being examined in this report. The average cost of service provision per person was provided in Table 1. To the extent that early intervention improves a person’s living independence, at least some of these costs could be reduced or avoided.

3.4.2 Estimating the costs of informal care

Reliance on informal care

Many people with a disability rely on informal care, such as by a family member. This in turn can affect that family member’s ability to work, as well as their quality of life and general well-being.

Some people who rely on informal carers will also use the funded services discussed above. For example, data reported by the AIHW showed that the percentage of service users that have an informal carer has averaged over 40% between 2003-04 and 2009-10.
For nearly two-thirds of the service users (65%), the care was provided by their mother. As service users age, it becomes more likely that their carer will be their spouse.

The following table shows people with a disability living in households with a co-resident primary carer in 2003, broken down by the type of disability.

<table>
<thead>
<tr>
<th>Disabling condition</th>
<th>Age of care recipient</th>
<th>All ages</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Under 65 years</td>
<td>Over 65 years</td>
</tr>
<tr>
<td></td>
<td>Number ('000)</td>
<td>%</td>
</tr>
<tr>
<td>Physical/ diverse</td>
<td>175.5</td>
<td>76.0</td>
</tr>
<tr>
<td>Sensory/ speech</td>
<td>101.5</td>
<td>44.0</td>
</tr>
<tr>
<td>Psychiatric</td>
<td>109.1</td>
<td>47.3</td>
</tr>
<tr>
<td>Intellectual</td>
<td>85.7</td>
<td>37.1</td>
</tr>
<tr>
<td>Acquired brain injury</td>
<td>38.1</td>
<td>16.5</td>
</tr>
<tr>
<td>Any of the above</td>
<td>230.8</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Methodologies used to estimate the costs of informal care

The AIHW looked at the costs of providing informal care as part of its 2009 report on Australia’s Welfare.\(^{55}\) It identified direct costs and indirect costs. The direct costs include costs such as specialised equipment and home modifications. It was recognised that these costs were really the costs of a disability, however many of these costs are borne directly by the carer or their household. It cited an estimate of these costs to be 29% of household income, on average.\(^{56}\)

It was noted that the more significant costs are the opportunity costs of caring, such as lost income because the carer is unable to work (or must reduce their hours of work), and missed opportunities for career advancement and further education. This can also affect retirement savings.

It is now well established that carers have reduced rates of participation in the workforce compared with non-carers. The SDAC\(^{57}\) found that 48% of primary carers aged 15-64 and 66% of non-primary carers aged 15-64 were employed at the time of the survey, compared with 73% of the non-carer population of working age (ABS 2008). Carers who were employed were more likely to work part-time – 54% of employed primary carers and 35% of employed non-primary carers worked part-time (less than 35 hours per week), compared with 29% of employed non-carers.\(^{58}\)

It was noted that for those carers who want to work, paid employment can not only bring financial security but also potential psychological and social benefits.

In addition to financial stress, the AIHW noted a number of other personal costs of caring, including effects on health and well-being and social life and engagement. Some carers have reported reduced health and vitality and some have had mental health problems, including depression (at rates well above the general population). It can also affect family relationships and functioning, with more adverse effects reported for families caring for a person with high care needs.

Caring responsibilities have also been seen to lead to relationship breakdown. The AIHW cites a paper by Edwards which reports that 30% of females aged between 31 and 50 had separated from their partner since they began caring.\(^{59}\)


\(^{57}\) This refers to the Australian Bureau of Statistics’ Survey of Disability, Ageing and Carers.


There are a number of different methods that can be used to estimate the economic value of informal care. The opportunity cost method measures the wages or benefits that are foregone by the caregiver as a result of their provision of informal care. The number of hours of work foregone need not have any direct relationship with the hours of care provided. That is, regardless of whether or not caring is a full-time responsibility (which in many cases it will be), the demands of a caring role could impede a carer’s ability to maintain a constant commitment to part- or full-time work.

It is generally approximated by the market wage in the economy. 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. However, there are a number of practical difficulties in ascribing values to things such as leisure time and this is therefore often excluded.

An alternative method is the replacement cost (or market cost) method. This 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.

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. 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.

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

63 Brouwer, W. et al. (1999).
64 Brouwer, W. et al. (1999).
rather than actual choice situations, thus reflecting revealed rather than stated preferences.\textsuperscript{65}

In 2010, Access Economics published an updated study analysing the economic value of informal care in Australia.\textsuperscript{66} The study, which was prepared for Carer’s Australia, 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).

It used the opportunity cost method to derive its lower bound estimate of the cost of informal care. Applying an average national wage rate of $968.10 per week to informal care, this method provided a total economic value of informal care in Australia of $6.5 billion.\textsuperscript{67}

Access Economics also applied the replacement cost method, which provided an upper bound estimate. It 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.\textsuperscript{68}

Although the differential between these two estimates is large, this reflects the fundamental differences in the methodologies used to derive the lower and upper bound. Overall, these estimates indicate that there is a substantial cost associated with informal care.

\textit{Determining the incremental cost of informal care}

In determining the costs associated with disability it is important to limit the focus to the incremental costs, that is, the additional costs that are only incurred as a consequence of disability. If the focus is on total costs, this could also capture costs that would also be incurred by individuals or families that do not have a disability (for example, a person without a disability will still incur healthcare costs) and hence will overstate the costs associated with the disability.

Caution must therefore be exercised when seeking to determine the incremental cost of informal care, particularly for children. Most parents will already spend a significant number of hours per week caring for children without a disability, particularly when

\begin{footnotes}
\item[66] Access Economics. (2010).
\item[67] This comprises earnings foregone for primary carers of $4.6 billion and $1.9 billion for non-primary carers.
\end{footnotes}
children are young. However, it is possible (and indeed likely) that on average, more hours are spent providing care for a child with a disability and/or the ‘intensity’ of that caring role is greater given the likely additional demands that are faced. It may also be more difficult to access mainstream childcare for children with a disability. Unfortunately, we do not have the data to capture all of those additional costs.

We can be more confident in ascribing incremental costs for people caring for an adult with a disability. In that case, any direct and indirect costs that arise as a consequence of the caring role should be solely attributable to the disability.

Approach applied in this study

Given the uncertainty associated with the valuation of informal care, we will also apply the opportunity cost and replacement cost methods.

For the opportunity cost method we can use the same data that is used to estimate employment impacts in section 3.3, being average weekly earnings. The ABS’s most recent Survey of Disability, Ageing and Carers (2009) reported that 68% of primary carers were women. Accordingly, we will apply a ‘blended’ estimate of average weekly earnings, reflecting a 68% weight given to average weekly earnings for females and 32% average weekly earnings for males. This results in an average weekly earnings estimate of $944, or $49,105 per annum. Assuming a 35 year working lifetime and a 3% discount rate, the present value of foregone earnings is $1.055 million.

The application of the replacement cost method requires assumptions regarding:

- the average number of hours spent providing care per week
- the value of an hour of care.

It may be possible to source estimates of the average number of hours spent caring per week for the different disabilities. For example, a study by Jarbrink, Fombonne and Knapp estimated that between 40 and 60 hours per week can be spent caring for a person with ASD. More generally, the ABS’s Survey of Survey of Disability, Ageing and Carers (2009) revealed the following distribution.

---


Figure 3  Primary carers aged 15 and over – hours per week spent caring

![Pie chart showing the distribution of hours per week spent caring.]


This shows that over 50% provide more than 20 hours per week, with around 36% providing more than 40 hours per week.

In terms of the value of an hour of care we will apply the estimate used by Access Economics, which is $31.04 per hour, or $31.81 in June 2011 dollars.

As with all of our estimates, applying average assumptions masks what can be considerable underlying variability in actual outcomes across the population. However, it is difficult to overcome that limitation without robust outcomes data across the population (or at least a large sample of the population), other than doing sensitivity analysis.

The most significant limitation of this approach is that it does not capture the indirect costs of caring (which can also be costs that are generally incurred by families of people with disabilities). As noted above, those costs cannot be readily quantified.

3.5  Healthcare expenditure

The additional healthcare costs incurred for children with disabilities will depend on the nature and severity of the disability, and can also be influenced by comorbid conditions. Children with physical disabilities will also incur additional costs for surgical and non-surgical interventions. There is some published data on the additional

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healthcare costs incurred for children with disabilities however most of this data is from overseas studies.

It is possible that early intervention can result in reduced healthcare expenditure for children with disabilities, although it may remain an important foundation for a child’s development (particularly for children with physical impairments). As for all of the benefits of early intervention, some evidence is needed to enable a link to be established between early intervention and improved healthcare outcomes (noting that most studies focus on cognitive and other functioning). The availability of this evidence is extremely limited. The impact of comorbid conditions is a further complicating factor.

Accordingly, this benefit will be more difficult to reliably quantify. If there is no reasonable supporting evidence it will not be included.

3.6 Quality of life

An impairment can adversely affect the quality of life for an individual, although again to varying degrees. This impact is officially termed the ‘Burden of Disease’ but for our purposes, we will simply refer to it as reduced quality of life. Such an impact is not tangible, however, attempts are still made to measure it. 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.

3.6.1 DALYs and disability weights

The World Health Organisation has developed a methodology to assess the reduction in quality of life as a consequence of illnesses and impairments, as part of a global study. A key metric emerging from this is the Disability Adjusted Life Year (DALY), which is:

...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:

---

- 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).

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 estimate the reduction in quality of life for a particular illness or condition.

For the purposes of this study we will limit our focus to the years of life lost due to disability (YLD). As we are focussing on the potential benefits per person, it is difficult to incorporate the impact of a possible reduction in the risk of premature mortality. In any case, this would also require robust evidence linking early intervention with a reduced probability of premature mortality, which is not available for all of our five disabilities (as it is not necessarily relevant to all disability types).

The YLD is measured based on disability weights. These weights range from 0 (which means living in a state of good or ideal health) to 1 (which is equivalent to death). For example, if a disability is assigned a weight of 0.5, it means that for each year of life, the equivalent of half a year of healthy life is lost due to disability. This in turn is seen to proxy the impact of disability on a person’s quality of life.

We have sourced disability weights from the AIHW. They are summarised in Table 3.

<table>
<thead>
<tr>
<th>Table 3 Disability weights</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD</td>
</tr>
<tr>
<td>-----</td>
</tr>
<tr>
<td>Autism: 0.55</td>
</tr>
<tr>
<td>Asperger’s: 0.25</td>
</tr>
<tr>
<td></td>
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<tr>
<td></td>
</tr>
</tbody>
</table>

3.6.2 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 WTP for health. This means estimating how much people are WTP for a small increase in the probability of survival.\(^75\) WTP estimates are typically gained by conducting a direct survey or some other preference method, which in turn enables economic researchers to estimate the Value of a Statistical Life (VOSL).

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.\(^76\)

Once a VOSL estimate has been obtained, it is possible to derive the Value of a Life Year (VOLY). This is taken to be a constant annual sum, where the present value of this annual amount (discounted at an appropriate rate), carries a present value that is equal to the VOSL. This value represents an important measure for use in economic studies.\(^77\) The VOLY is estimated through the equation:

\[
\text{VOLY} = \frac{\text{VOSL}}{A} \quad \text{[Equation 1]}
\]

\[
A = \frac{1-(1+r)^{-n}}{r}
\]

- \(n\) = 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.\(^78\)

Estimates for VOSL and VOLY

Table 4 provides the VOSL estimates obtained by a number of studies from around the world.

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Table 4  VOSL estimates

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


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.

A 2003 Australian study 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 Australian dollars. 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.79

Allowing for 40 years of healthy life remaining and a discount rate of 3%, 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. 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).80

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.81 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). Reference is made to Equation 1 above for the calculation method.

We will adopt Access Economics’ recommended estimate for our study. This estimate was in 2006 dollars. The mid-point estimate in June 2011 dollars is $288,965.

Summary: valuing improvements in quality of life

The annual impact of a reduction in quality of life for an individual is estimated by multiplying the disability weight by the VOLY (if this was a population study, we would multiply the total number of years lost through disability, or DALYs, by the VOLY).

If the quality of life for an individual is improved, it will result in a reduction in the disability weight. This in turn will result in a reduction in the VOLY, that is, a reduction in the estimated ‘cost’ of disability, which could also be viewed as the value of any improvement in quality of life.

While it is currently not possible to accurately measure the reduction in the disability weight that is likely to occur as a consequence of early intervention, we can hypothesise the impact if certain gains are made.

3.7 Impact on families

As discussed in section 2.1.4, having a child with a disability can introduce a range of additional challenges and stressors for families (some, but not all of these, would also be recognised as the costs of providing informal care).

Section 2.1.4 also discussed evidence which shows that early intervention can materially impact family quality of life. At this stage, however, these impacts are very difficult to measure, noting that some of the research is now directed towards measuring family quality of life.82

In the absence of an accepted measurement methodology we have not sought to quantify these benefits here. However, these benefits could potentially be significant and should not be ignored.

The potential benefits of early intervention for each of our five disabilities of interest will now be explored.

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4 Down syndrome

4.1 Overview of Down syndrome

Down syndrome is a chromosomal anomaly, which in most cases is caused by an extra copy of chromosome 21 being present in all of the body’s cells. The presence of this additional chromosome accounts for 95% of people with Down syndrome. The other two forms of Down syndrome are Mosaic Down syndrome (1-2%) and Translocation Down syndrome (3-4%).

Over 100 features have been described in Down syndrome. Children and adults with Down syndrome vary enormously in appearance, physical development personality, temperament, and range of abilities, including intellectual capability.

Among the stereotypes that are being dispelled are that Down syndrome is a homogeneous condition in which all individuals are highly similar in intellectual, behavioural, and other characteristics and that the expected intellectual, developmental, and functional outcomes are poor. As a variety of research shows, although Down syndrome is an identifiable condition with many characteristics shared across individuals, there is considerable variation among individuals with Down syndrome—medically, physically, intellectually, and psychologically.

Each individual has their own unique personality, capabilities and talents.

Down syndrome is one of the main causes of cognitive delay in the population. Most people with Down syndrome are able to read and write through learning, although often at a slower rate. Evidence shows that children with Down syndrome learn in a different manner to their typically developing peers, and have a different style of assimilating information.

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There is also a wide range of health conditions associated with Down syndrome. Some people with Down syndrome have many serious medical needs and some have few. The most common, heart anomalies, affects as many as 50 per cent of children with Down syndrome. Other people have a higher than average incidence of heart and respiratory conditions and sensory impairments. However, improvements in medical treatment have dramatically improved the health outcomes and life expectancy of people with Down syndrome.

### 4.2 Prevalence

According to the Down Syndrome Association of Queensland, in Australia a baby with Down syndrome is born approximately one in every 700 births. A 2000 report by the AIHW found that incidence rates for Down syndrome in birth was around one in 781 people during the period 1987 to 1996. Another AIHW report indicates that during 1998 to 2003, one in 909 newborns were diagnosed with Down syndrome.

As outlined above, there has been a dramatic increase in the life expectancy for people with Down syndrome. As a result of improved medical knowledge and health care, the life expectancy of a person with Down syndrome now approaches 60 years.

### 4.3 Early Intervention Strategies

Down syndrome can cause delays in physical, intellectual and language development. This in turn can affect functioning in a number of domains, including daily living skills, motor skills, communication and socialisation.

Early intervention strategies have been developed to target improvements in a number of areas such as motor skills, cognitive skills, speech and language, working memory, reading and writing, number skills and social development and behaviour. Interventions can be provided by a range of professionals including special educators, speech therapists, occupational therapists and social workers. Importantly, as will be outlined below, parents and caregivers also have a critical role to play in facilitating the development of a child with Down syndrome.

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91 Down Syndrome Association of Queensland Inc Information Sheet.


As with all of the disabilities that are examined in this review, it is critical to initiate interventions as early as possible. Given Down syndrome is typically able to be diagnosed at or shortly after birth, there should be no reason why this can’t occur. Iarocci et al observe:96

The chromosomal anomaly in DS has powerful and specific influences on development, the consequences of which may be considered so great by adulthood that environmental interventions have relatively little to contribute. Conversely, in the early stages of development, the prognosis of infants and young children with DS is more promising, as recent evidence in the neurobehavioral sciences indicates that brain development is quite malleable and responsive to early pre-, peri-, and postnatal influences.

A summary of our review of the literature is contained in Appendix 10A. We have examined efficacy and effectiveness studies. While there are a number of studies that address efficacy, robust research on the effectiveness of actual strategies is limited. Methodological issues are a common problem in effectiveness studies (and not just for Down syndrome interventions).

It is also important to recognise the difficulties in designing evaluation studies (as outlined in section 2), which is a function of a number of factors, including the significant variability in the development progress among children with Down syndrome, which is also influenced by complicating medical conditions and other environmental factors.

As noted by Nilholm, environmental influences are important. Their presence means that any differences observed in a group of children or a child with Down syndrome cannot necessarily always be attributed to Down syndrome:97

In this perspective, controlled studies of children with Down syndrome imply the occurrence of a universal child with Down syndrome, i.e. a child whose characteristics could be mapped out separated from the prior transactions of the child with her/his environment.

Recognition of environment and context therefore needs to be considered. Nilholm suggests that two types of studies are needed: the typical scientific studies based on

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larger samples, as well as case studies with detailed, descriptive accounts of individual children within a particular context.

A brief overview of the areas that are examined is provided below. This is not intended to be exhaustive. For the purpose of this review we have sought to focus on more recent studies across a range of areas and provide examples of where and how interventions can be effective, recognising the significant advances that have been made in Down syndrome research in recent decades, and we expect will continue to be made into the future.

4.4 Key areas for early intervention in children with Down syndrome

4.4.1 Speech, language and communication

Children with Down syndrome can experience significant delays in speech development, which can negatively impact other areas of functioning. They can also have difficulties with auditory processing and language development, as well as word recognition and language comprehension.

Aparicio and Balana note that the marked hypotony shown by Down syndrome babies in the first year of life is a determining factor in their subsequent language development. As this will impact interactions with parents and caregivers, the family environment can inadvertently contribute towards deterioration in the language development of infants with Down syndrome. Effective early intervention that involves families can assist parents in understanding the problem and help them to work more effectively with their child.

Early intervention can include strategies and techniques to enhance communication. Strategies can also be employed to improve reading skills, including Phonological
Awareness Training and Silent Reading. Examples of other types of strategies that have been employed are provided in Appendix A.

4.4.2 Motor development

Motor development plays an essential role in the development of all children. From their earliest years, the development of motor skills can provide the basis for many other areas of development. The basic everyday actions of reaching, standing, moving, and manipulating depend upon proficient motor development. If motor development is delayed or impaired, there can be consequences for the competence of the individual in a range of settings. Motor functioning and muscle strength are pivotal for achieving postural, manipulative and locomotor milestones.

Interventions focus on gross and fine motor skills, as well as the interactions between motor and perceptual processes. In terms of gross motor skills (that is, skills such as walking that use large muscle groups), a major goal of early intervention is to enhance the rate of acquisition of motor skills and to prevent the occurrence of secondary problems resulting from the child’s use of compensatory strategies (such as ‘fixing’ or ‘locking’ joints to overcome the effects of low motor tone).

It has been observed that on average, infants with Down syndrome may not begin walking until one year later than infants that do not have a disability. Walking has multidimensional impacts, with the potential to influence cognitive, social and subsequent motor development. Treadmill training has also been identified as a strategy that can be effective in encouraging infants with Down syndrome to walk (it can also be easily implemented in the home).

Massage therapy may enhance development for children with Down syndrome, such as improve muscle tone and motor development. Physical therapy can help to prevent compensatory movement patterns that individuals with Down syndrome are prone to.

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developing, which might lead to orthopedic and functional problems if not corrected.\textsuperscript{108}

Fine motor skills involve the use of smaller muscle groups, such as the ability to hold and reach objects. Physical therapy and practice in achieving these and subsequent milestones can assist a baby with Down syndrome in a number of key developmental areas.\textsuperscript{109} It has also been shown that families can benefit from involvement in early fine motor interventions that assist them to understand and facilitate the development of their child.\textsuperscript{110} Given the critical role that the family environment can play in this development, the involvement of parents in motor interventions can have the potential to stimulate and increase the child’s reactivity and initiative.

Motor system does not function in isolation. Motor processes interact with perceptual processes and there is some evidence to suggest that children with Down syndrome have impairments in perceptual-motor coupling.\textsuperscript{111} Perceptual motor skills work in complement with cognitive and sensory-motor development, and are largely responsible for an individual’s ability to engage in athletic activities and interact with his or her environment. Examples of perceptual motor skills include hand-eye coordination, body-eye coordination, auditory language skills, postural adjustment, and visual-auditory skills. Young children can practice perceptual motor skills through active play, object manipulation, drawing, blocks, and various other forms of physical activity.\textsuperscript{112}

Perceptual motor development interventions aim to nurture and shape the development of interpersonal skills and social competence of infants. Early perceptual-motor competencies (such as eye gaze and joint attention to objects, people and environment) are taught within a play context to maximise the quality of early dyadic interactions between infants with Down syndrome and their parents.


\textsuperscript{112} http://www.ehow.com/facts_5900878_perceptual-motor-skills_.html
As outlined above, concerns have been raised in the literature regarding the effectiveness of early intervention services for motor functioning. Mahoney and Perales postulate two reasons for this:\(^{113}\)

- parents are not being involved as active participants in the intervention; and
- traditional models of motor intervention have been focusing on activities that are incompatible with current theory and research.

The importance of parent involvement is discussed below. In terms of the underlying theory, for example, they advocate strategies based on contemporary models such as Dynamic Motor Theory, which says that motor development is a consequence of children constructing solutions to motor problems. Interventions can therefore be targeted to encourage child-initiated motor activity and problem solving.

### 4.4.3 Parent-child relationship/family intervention

There is now a growing body of research on the benefit of family involvement in early intervention programs, including for children with Down syndrome.\(^{114}\) Parent-child interactions can inadvertently hinder development and contribute to further developmental declines. If provided with the appropriate information and skills, parents can engage in effective interactions to prevent this decline and promote development.

The emphasis of parent or relationship-focused interventions is to foster, facilitate, and optimise interactions between children with Down syndrome and their carers in order to facilitate development, increase parental satisfaction and maintain family well-being. The long-term developmental goals are to improve the child’s social competence and community integration and adaptation to family life cycle transitions.\(^{115}\)

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Participation in early intervention programs not only connects parents with professionals who have a detailed knowledge of their child’s disability, but it also connects them with other parents to share experiences. These groups can provide social and emotional support as parents work through their initial adjustment, in addition to providing an arena for the exchange of information about services and resources.

### 4.4.4 Future directions for research

As for all of the disabilities that have been examined in this review, our knowledge and understanding of Down syndrome continues to grow and evolve. This in turn contributes to the design and implementation of early intervention strategies. As these strategies evolve, their effectiveness then needs to be assessed.

Historically, there have been some concerns regarding the effectiveness of early intervention strategies for children with Down syndrome, for example, interventions that have been designed to target improvements in motor skills. Other concerns are that any gains have only been short-term. Our review of the literature confirms that while robust effectiveness studies need to continue to be a priority for the future, early intervention has the potential to materially improve outcomes for children with Down syndrome.

Further, in those areas where effectiveness studies have yielded disappointing results, rather than be seen to affirm a conclusion that early intervention cannot be effective, this has prompted researchers to further question and understand why this might be the case. In addition to potentially increasing our understanding of the nature of the impairment, including what may work best and under what circumstances, these findings then contribute to the ongoing design of early intervention programs and how they are delivered. For example, as outlined above, one study that has examined the effectiveness of motor interventions has cited inadequacies in family involvement in the intervention as a possible reason for this.116

Spiker and Hopmann conclude that the first generation of early intervention research for children with Down syndrome has successfully addressed the efficacy of early intervention.117 The next generation is focussing on more specific questions about strategies, goals, child and family characteristics and outcomes. For example, they identify that more research is needed in areas such as: the effect of program duration and intensity; the relationship between individual differences among children and families and program efficacy; and effects of programs in integrated settings.

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Capone reiterates the need to understand where and why intervention works.\textsuperscript{118} It was proposed that intervention should not necessarily aim to accelerate development, but support it by teaching specific strategies as neuromaturation proceeds, which will also prevent declines in development from occurring. Capone considers that development-based therapies will become increasingly specialised and more prominence may be given to neurocognitive therapies.

Light and Drager observe that effective early intervention requires the application of both science and art. The science involves the implementation of evidence-based procedures that are monitored for effectiveness and evaluated for outcomes. In terms of art, this involves “the belief and the commitment to the right of all individuals to express themselves fully and seek their full potential”\textsuperscript{119}.

### 4.5 Cost of Early Intervention

We have only accessed information from one service provider as to the cost of an early intervention program for children with Down syndrome. This service provider delivers a family-focused program, enabling the child and parent to interact with a therapist in a play-based setting (on average, one hour of therapy is provided per week). Individual therapy sessions and playgroups are also conducted. Based on the information provided by this service provider, the annual cost of providing the program is around $7,000 per child per year for eight years (on average), resulting in an average total cost of $56,000 per child.\textsuperscript{120} We haven’t discounted these costs over those eight years. This is a conservative assumption (and recognises that there may be other costs that we have not captured).

We recognise that different programs involve different costs. This estimate should therefore be considered indicative only.

### 4.6 Benefits of Early Intervention

As outlined above, there is very limited evidence available to enable us to draw any robust conclusions regarding the long-term impact of early intervention for children with Down syndrome, and in particular, measure likely outcomes across the population or assign probabilities to improvements. However, studies that have examined the efficacy and effectiveness of early interventions for children with Down


\textsuperscript{119} Light, J. & Drager, K. (2010). p.5.

\textsuperscript{120} It also assumes that therapy services are costed at market rates ($120 per hour).
syndrome show that participation in early intervention can provide an essential foundation for the development of a child with Down syndrome, by promoting positive development and minimising decline or regression. It can also yield significant positive impacts for parents and families.

In the absence of robust outcomes studies, we can only hypothesise as to possible long-term impacts. The outcomes can also be expected to vary between individuals, recognising the heterogeneity in the characteristics of each child, the impact of environmental factors and their response to intervention. However, based on the research that has been done, achieving positive long-term outcomes from early intervention for children with Down syndrome is considered plausible. Further research is needed to be able to robustly identify and measure these outcomes over the longer term, including understanding which strategies work best and under what circumstances.

### 4.6.1 Education

**Base case**

While children with Down syndrome can experience learning difficulties, as outlined in section 4.4.1, many are educated in a mainstream school environment. However, some children with Down syndrome will attend a special school and/or receive additional services and supports. We do not have specific data on the proportion of children in Australia with Down syndrome that attend a special school.

**Estimating potential benefits**

As is stated in section 3.2, the additional per person cost of providing special education services to students with disabilities is estimated at $15,367 per annum. If:

- in the absence of early intervention, a child with Down syndrome would have needed to attend a special school; and
- early intervention results in a material improvement in outcomes for that child to the point where they can attend a mainstream school with our without support;
- or,
- in the absence of early intervention, a child with Down syndrome would have needed to attend a mainstream school with support; and

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• early intervention results in a material improvement in outcomes for that child to the point where they can attend a mainstream school without support, this cost is avoided and therefore represents a benefit from early intervention.

If the entire cost is avoided, over 12 years of schooling, the total benefit (in Present Value terms) is estimated at $153,000 using a discount rate of 3% (base case) and $128,800 using a discount rate of 6%.

This estimate is considered to be the upper bound estimate for the benefits of early intervention in relation to the reduction in special education costs. On average, the actual benefits for an individual are likely to lie between $0 and $153,000, as rather than completely negate the need for special education services, early intervention may reduce the intensity of special education services required for a child (i.e. the actual annual benefit may be some portion of the estimate of $15,367).

We have no data to estimate the cost savings that may be realised and in practice, this will vary for each child. In the absence of this data, we could take the mid-point (that is, assume that 50% of the costs are avoided), recognising that the actual cost savings for a child could be higher or lower than this.

There may also be other benefits for the child in attending a mainstream school that have not been captured here.

4.6.2 Improved employment outcomes

Base case

Many people with Down syndrome are productive members of the workforce (in either competitive employment or supported environments). However, others may be unable to work as a consequence of their impairments. As outlined in section 3.3, underemployment and reduced productivity are also potential problems. We have no employment statistics for people with Down syndrome of working age in Australia.

Impact of early intervention

There have been no longitudinal studies conducted that have assessed the impact of early intervention on the employment outcomes for individuals with Down syndrome. To the extent that early intervention is able to materially improve the development path for a child with Down syndrome, and therefore improve their educational performance as well as their ability to function in different environments, it is plausible that early intervention could lead to improved employment outcomes for people with Down syndrome.
There are a number of caveats to this assumption. First, there are other aspects of functioning that will impact educational attainment and/or employment outcomes, including social and communication skills (noting that early intervention also targets improvements in these skills). Second, the outcomes achieved for different individuals will vary considerably across the spectrum, reflecting the variations in the nature and extent of the impairment as well as the child’s response to early intervention. Third, employment outcomes are influenced by factors external to the individual.

**Estimating potential benefits**

Section 3.3 contains the estimates and parameters used to estimate the productivity benefits associated with improved employment outcomes from early intervention. The assumptions applied to full-time employment are:

- based on ABS data, an average annual salary for all employees of $53,040 ($65,052 for males and $41,600 for females); and

- based on the parameters in section 3.3, a lifetime estimate for total earnings across all employees (in Present Value terms) of $1.14 million ($1.398 million for males and $0.894 million for females) using a 3% discount rate.

In the event that early intervention enables an individual to obtain part-time employment at the ABS rate for average annual earnings, the corresponding estimates are as follows:

- average annual earnings for all employees of $33,150 ($40,658 for males and $26,000 females). We have based this on 62.5% of full-time earnings; and

- lifetime estimate for total earnings across all employees (in Present Value terms) of $712,000 ($874,000 for males and $559,000 for females) using a 3% discount rate.

Early intervention may not necessarily enable all individuals with Down syndrome to obtain employment at a rate (salary) that is commensurate with the entire population. At minimum, a person’s salary (in competitive employment) will be based on the minimum wage. The benefit associated with this outcome, as per section 3.3, is $30,644 per annum or $0.658 million in Present Value terms over a 35 year working life. The corresponding estimates for an individual that is able to secure part-time employment at the minimum wage are $19,153 per annum or $412,000 over a 35 year working life.

These estimates represent the benefit that will be achieved if early intervention enables an individual with Down syndrome - who would otherwise have been unemployed - to obtain competitive employment. They can also be used to estimate the benefits of
reducing underemployment, for example, where a person who would have otherwise only earned the minimum wage can secure a job at the average wage.

The table below presents the annual and lifetime benefits relating to gains in productivity as discussed above. We have also shown the sensitivity of the lifetime benefit estimates to a 6% discount rate instead of our base case assumption of 3%.

<table>
<thead>
<tr>
<th>Benefit</th>
<th>Annual benefit ($/yr)</th>
<th>Lifetime benefit – 3% discount rate</th>
<th>Lifetime benefit – 6% discount rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Obtain full-time employment at average wage</td>
<td>53,040</td>
<td>1,140,000</td>
<td>769,000</td>
</tr>
<tr>
<td>Obtain part-time employment at average wage</td>
<td>33,150</td>
<td>712,000</td>
<td>481,000</td>
</tr>
<tr>
<td>Obtain full-time employment at minimum wage</td>
<td>30,644</td>
<td>658,000</td>
<td>444,000</td>
</tr>
<tr>
<td>Obtain part-time employment at minimum wage</td>
<td>19,153</td>
<td>412,000</td>
<td>278,000</td>
</tr>
</tbody>
</table>

Note: Part-time estimates are generated based on 25 hours per week (i.e. 62.5% of full-time rate). For presentation purposes the lifetime estimates have been rounded.

Based on these estimates, if a person would have otherwise been unemployed but obtains competitive employment as a consequence of improved outcomes achieved as a direct result of early intervention, this could increase economic productivity by $412,000 over their working lifetime (based on part-time employment at the minimum wage). A more optimistic assumption is that they gain full-time employment at the average wage, which would result in an increase in economic productivity of $1.14 million. They may secure employment at a rate above the average wage.

As outlined above, we can also use these estimates to measure the potential benefits of reducing underemployment. For example, if a person who would have otherwise only earned the minimum wage can secure a job at the average wage, the productivity benefit will be based on the difference between their earnings based on the average wage and their earnings based on the minimum wage.

As discussed in section 3.3, there are a number of important qualifications to this approach. In particular, it assumes that the employment of the person results in a net increase in productivity in the economy, which equates to their salary.

As outlined above, the actual outcomes will vary anywhere along this spectrum. Some people with Down syndrome will have gained employment without early intervention. Others who have been through an early intervention program may still not gain competitive employment. However, the life outcomes for these individuals and their families may still be improved in other areas.
4.6.3 Improved living independence

Base case

Again, a variety of outcomes could be expected for people with Down syndrome in terms of living independence, ranging from reliance on formal care services, to living with parents, to living in a semi-independent or fully independent environment.

Impact of early intervention

As previously stated, there is no robust evidence available that enables us to directly estimate the impact of early intervention for children with Down syndrome on their ability to live independently as adults. Having noted this limitation, it is still considered appropriate to provide estimates around the potential for early intervention to produce benefits by improving living independence as we consider that such outcomes are plausible.

Estimating potential benefits

The benefits of improvements in living independence could manifest in one or both of the following:

- reduction in the cost associated with formal services provided (i.e. accommodation support, community access and support, respite care, etc.); and/or
- reduction in informal care required.

Formal care

As stated in section 3.4, it has not been possible to generate estimates of the costs incurred in providing formal care services for all of the specific disabilities. However, it is possible to estimate the cost of services provided to individuals across all disabilities. It is also considered reasonable to conclude that people with Down syndrome could require formal care services.

The estimated cost per person per year, as well as the estimated lifetime costs, is provided in the table below. Again, we have estimated the lifetime benefits assuming a discount rate of 3% (base case) and 6%.
Table 6  Per person expenditure on disability support services

<table>
<thead>
<tr>
<th>Service</th>
<th>Annual cost ($/person)</th>
<th>Cost over 20 yrs @ 3%</th>
<th>Cost over 40 yrs @ 3%</th>
<th>Cost over 20 yrs @ 6%</th>
<th>Cost over 40 yrs @ 6%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accommodation support</td>
<td>67,101</td>
<td>998,300</td>
<td>1,551,000</td>
<td>769,600</td>
<td>1,009,600</td>
</tr>
<tr>
<td>Community support</td>
<td>6,740</td>
<td>100,300</td>
<td>155,800</td>
<td>77,300</td>
<td>101,400</td>
</tr>
<tr>
<td>Community access</td>
<td>11,429</td>
<td>170,000</td>
<td>264,200</td>
<td>131,100</td>
<td>172,000</td>
</tr>
<tr>
<td>Respite</td>
<td>9,937</td>
<td>147,800</td>
<td>229,700</td>
<td>114,000</td>
<td>149,500</td>
</tr>
<tr>
<td>Employment support</td>
<td>5,469</td>
<td>81,400</td>
<td>126,400</td>
<td>62,700</td>
<td>82,300</td>
</tr>
</tbody>
</table>

Note: Data does not cover all expenditure on services by people with disabilities – only relates to services funded under the National Disability Agreement. For presentation purposes the lifetime estimates have been rounded.


As the above table shows, to the extent that a person with Down syndrome is a consistent user of formal care services, and early intervention reduces their need for these services, the benefits could be up to $1.55 million (this is the avoided cost of long-term accommodation support). Caution must be exercised in making any generalisations from this data, however, given the nature and extent of service use and outcomes achieved will vary between individuals. For example, for some individuals who have received early intervention, they may still need to rely on formal services, however the intensity of their service use may be reduced, which would still yield a cost saving.

Informal care

In relation to informal care, as discussed in section 3.4.2, we are applying two approaches to estimating the potential benefits of early intervention in relation to the provision of informal care – the opportunity cost method and the replacement cost method. In the absence of any specific data on the impact of early intervention on informal care, we can only hypothesise on possible outcomes. For example, the following table identifies three scenarios, ranging from a small reduction to a significant reduction, and shows the cost impact under each approach.
Table 7  Potential improvement scenarios in terms of informal care provided

<table>
<thead>
<tr>
<th>Improvement scenario</th>
<th>Opportunity cost approach</th>
<th>Replacement cost approach</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Impact</td>
<td>Impact</td>
</tr>
<tr>
<td></td>
<td>Consequence</td>
<td>Consequence</td>
</tr>
<tr>
<td>Small (e.g. reduction of 5 hrs of informal care per week)</td>
<td>Will not necessarily improve carer’s ability to maintain employment</td>
<td>Reduction of 5 hours of informal care required</td>
</tr>
<tr>
<td>Moderate (e.g. reduction of 15 hours of informal care per week)</td>
<td>Carer may be able to secure a part time job</td>
<td>Increase in productivity based on part-time contribution</td>
</tr>
<tr>
<td>Significant (e.g. reduction of 30 hours of informal care per week)</td>
<td>Carer may be able to secure full-time job</td>
<td>Increase in productivity based on full-time contribution</td>
</tr>
</tbody>
</table>

As can be seen from the above table, the potential benefits attributable to early intervention will vary significantly depending on the approach that is adopted. For example, consider the scenario in which the amount of informal care required is reduced by five hours per week as a result of early intervention. Under the opportunity cost approach, this would not result in any benefits being estimated due to the absence of a productivity impact (as reducing the amount of informal care provided by only five hours per week is unlikely to allow the carer to obtain employment). Alternatively, under the replacement cost approach, the benefit will be equal to the imputed market rate for informal care multiplied by five hours per week.

The assumptions to be applied to estimate the benefits from reduced informal care are set out in section 3.4.2 and are as follows:

- opportunity cost approach: average weekly earnings of $944 or $49,105 per annum for full time employment and $30,691 for part time employment (part time estimate based on 25 hours per week); and
- replacement cost approach: a value of $31.81 per hour of care.

The table below takes the three potential improvement scenarios from Table 7 and estimates the annual benefit per person resulting from early intervention under the two approaches.
Table 8  Estimation of potential annual benefits of early intervention in relation to informal care per person

<table>
<thead>
<tr>
<th>Improvement scenario</th>
<th>Opportunity cost approach</th>
<th>Replacement cost approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small (5 hr/week reduction)</td>
<td>-</td>
<td>$8,300</td>
</tr>
<tr>
<td>Moderate (15 hr/week reduction)</td>
<td>$30,700*</td>
<td>$24,800</td>
</tr>
<tr>
<td>Significant (30 hr/week reduction)</td>
<td>$49,100</td>
<td>$49,600</td>
</tr>
</tbody>
</table>

*a This estimate is based on an individual with a part time job working 25 hours per week (i.e. 62.5% of the estimate for full-time employment). Numbers have been rounded to the nearest hundred dollars.

Over a 35 year working life, the total benefits (in Present Value terms) are as follows:

- under the opportunity cost approach:
  - $659,700 from a moderate reduction in informal care requirements ($445,100 using a discount rate of 6%); and
  - $1.055 million from a significant reduction in informal care requirements ($711,900 using a discount rate of 6%);

- under the replacement cost approach:
  - $178,300 from a small reduction in informal care requirements ($120,300 using a discount rate of 6%);
  - $532,900 from a moderate reduction in informal care requirements ($359,600 using a discount rate of 6%); and
  - $1.066 million from a significant reduction in informal care requirements ($719,100 using a discount rate of 6%).

The results presented above demonstrate the wide range of potential benefits resulting from a reduction in informal care through early intervention. Even if the benefits lie between the small and moderate scenarios, the benefits are still potentially significant, recognising the other benefits that could also arise that are not captured here, such as an improvement in the carer’s own well-being.

4.6.4  Improved quality of life

Base case

As previously stated in section 3.6, the focus of this study in terms of assessing quality of life impacts has been limited to YLD (that is, it does not focus on premature mortality). For early intervention, this is measured based on a disability weighting of 0.35 for a person aged under 40 and 0.650 for a person over 40 (see Table 3). This
disability weighting is then applied to the estimate for the VOLY of $288,965 (June 2011 dollars) to produce an annual per person cost of:

- $101,138 (person under 40)
- $187,827 (person over 40).

These estimates represent the average annual cost of a reduction in quality of life for a person with Down syndrome per year.

Impact of early intervention

The impact of a disability on quality of life is determined by a range of factors including physical and mental health issues, living independence, mobility, employment etc. While there is a lack of longitudinal studies assessing the impact of early intervention on these factors for individuals with Down syndrome, we consider that some improvement is plausible.

The benefits from improvements in quality of life as a result of early intervention can be estimated by assessing the potential impact on the disability weighting for individuals with Down syndrome under different scenarios. The benefits are then estimated by applying the assumed reductions to the disability weighting (which as outlined in section 3.6.1, represents the portion of a year of healthy life lost due to disability), which is then applied to the VOLY in order to value the improvement in quality of life per annum.

Estimating potential benefits

As stated above, the disability weightings for Down syndrome are 0.35 for a person aged under 40 and 0.65 for a person over 40. If quality of life improves, this weighting will be reduced. Three reductions were applied to this weighting to assess the potential benefits of early intervention in terms of quality of life - a conservative reduction of 10%, a significant reduction of 30%, and a ‘mid-point’ estimate of 20%. We have applied these same reductions to each age group. There is no evidence available to support the percentage reductions. The intention is to show what the benefit might be if such improvements were realised.

As the disability weightings are materially different for people with Down syndrome aged under 40 and over 40, we have estimated the impacts on each age group separately.

These reductions were applied to the VOLY ($288,965) to derive an estimate of the annual benefit. For a person under 40, the annual per person benefits estimated were as follows:
- $10,114 under the conservative scenario
- $20,228 under the median (or mid-point) scenario
- $30,341 under the significant improvement scenario.

For a person aged over 40, the annual per person benefits are:
- $18,783 under the conservative scenario
- $37,565 under the median (or mid-point) scenario
- $56,348 under the significant improvement scenario.

A present value of the lifetime outcomes is also estimated over 20 and 40 years of adult life (from age 20) using discount rates of 3% (base case) and 6%, as shown in the following table (numbers have been rounded to the nearest hundred dollars).

<table>
<thead>
<tr>
<th>Improvement scenario</th>
<th>Age 20 to 40 (20 yrs)</th>
<th>Age 40 to 60 (20 yrs)</th>
<th>Age 20 to 60 (40 yrs)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>3% disc. rate</td>
<td>6% disc. rate</td>
<td>3% disc. rate</td>
</tr>
<tr>
<td>Conservative</td>
<td>150,500</td>
<td>116,000</td>
<td>279,400</td>
</tr>
<tr>
<td>Median</td>
<td>300,900</td>
<td>232,000</td>
<td>558,900</td>
</tr>
<tr>
<td>Significant</td>
<td>451,400</td>
<td>348,000</td>
<td>838,300</td>
</tr>
</tbody>
</table>

a For presentation purposes the estimates have been rounded.

Based on the scenarios modelled above, the conservative scenario of a 10% reduction in the disability weighting for 20 years of adult life between ages 20 and 40 produces a present value benefit of $150,500. A more optimistic scenario could yield benefits of $451,400 over the same time period. The longer these improvements are maintained throughout adult life, the higher the benefits.

This shows that if even small improvements are achieved (and sustained for some period), the benefits are significant. Recognising the issues involved in reliably measuring quality of life impacts (as discussed in section 3.6), even small improvements in this metric alone could far outweigh the cost of early intervention.

### 4.6.5 Improved health outcomes

#### Base case

As discussed previously, people with Down syndrome can experience a number of health problems (some of them potentially severe) throughout their life, although the treatment and management of these issues have improved. For example, a US study by
Boulet et al (2008) found that mean and median healthcare costs for children aged zero to four years of age with Down syndrome were 12 to 13 times the costs incurred for children without Down syndrome.122

**Impact of early intervention**

We have no evidence linking early intervention for children with Down syndrome to health care outcomes. Despite the plausibility of improvements in outcomes across a range of areas, we do not consider that we have a sufficient evidence base to draw a direct linkage between early intervention and health care outcomes. Accordingly, we have not sought to ascribe any benefits here.

**4.6.6 Improved quality of life for families**

There is considerable evidence suggesting that caring for a child or adult with a disability can have a significant impact on the family, including families of children with Down syndrome (refer Appendix A). While some of the costs associated with this impact are accounted for under the costs of informal care, there are also other costs including the impacts of higher levels of stress in the family environment (e.g. marital breakdown).

As previously stated in section 3.7, there is currently no accepted methodology available for estimating these costs and as a result they have not been included in this study. We consider it reasonable to assume that early intervention has the potential to generate significant and positive benefits for families, as is evidenced by some of the studies contained in Appendix A. Accordingly, while these benefits cannot be directly valued they should not be ignored.

**4.7 Summary of benefits from early intervention**

In summarising the results of this assessment it is firstly necessary to reiterate the absence of robust data on long-term outcomes for individuals with Down syndrome that receive early intervention. However, we consider that it is reasonable, based on the evidence that is available, to conclude that early intervention does have the potential to generate material benefits.

The benefits of early intervention are also likely to vary considerably between children with Down syndrome. These benefits are subject to a number of factors, including:

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• the nature and extent of the child’s impairments before intervention
• their age of referral to an intervention program
• the nature and intensity of the intervention received
• the child’s response to the intervention
• the influence of other environmental and contextual factors
• the presence and influence of comorbid conditions.

Accordingly, it is not appropriate to provide point estimates of the total benefits or even a potential range of outcomes. The ability to provide such estimates would be improved by robust long-term outcome studies as this would provide evidence in relation to the early intervention strategies that work best for children with Down syndrome under particular conditions.

In section 9, we hypothesise a range of potential scenarios for a child with a disability that has received early intervention. This recognises the wide spectrum of outcomes that could be observed between different disabilities and for any group of children with the same disability. We also recognise that the costs of early intervention can vary according to the nature of the program and the needs of the child and the family.

These scenarios hypothesise different combinations of outcomes, recognising that the outcome achieved in each area must be referenced to the outcomes that the child would otherwise have achieved in the absence of early intervention. Any one of these outcomes is considered plausible for a child with Down syndrome, having regard to the variables listed above. However, we cannot ascribe any probabilities to any of these scenarios being achieved.

Overall, this shows that early intervention for children with Down syndrome has the potential to generate significant positive economic benefits. Apart from the fact that this does not capture the full spectrum of outcomes that may be achievable, it is also important to remember that there are also other benefits that have not been quantified, such as improvements in the quality of life for families. Those benefits alone may be material.
5 Autism

5.1 Overview of the disability

ASD is a developmental disorder characterised by impairments in social activity, communication and imagination. It is defined as a spectrum disorder reflecting the fact that people with ASD vary significantly in their personalities, strength and weaknesses, as well as their response to treatment. Specifically, there is no one symptom or behaviour that defines individuals with ASD. Additionally, there are no distinguishing physical characteristics, and specific causes are as yet unknown, although genetic factors are thought to play a significant role.

ASD includes a number of conditions, including (the following is based on the DSM-IV classifications):

- autistic disorder
- Asperger’s Syndrome
- Childhood Disintegrative Disorder (CDD)
- Pervasive Developmental Disorder that is Not Otherwise Specified (PDD-NOS)
- Rett’s Syndrome.

The World Health Organisation provides the following definition for autism:

…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 relation to each of these domains determines which of the five sub-groups that individual is diagnosed under. Individuals with autism will

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123 The Diagnostic and Statistical Manual of Mental Disorders, fourth edition. Proposed revisions for the fifth edition will require the following four criteria to be met: (1) persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays; (2) restricted, repetitive patterns of behavior, interests, or activities; (3) Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities); and (4) symptoms together limit and impair everyday functioning.

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

5.2 Prevalence

5.2.1 Recent prevalence estimates

The most recent comprehensive autism prevalence study conducted in Australia is MacDermott et al (2007).125 This study reported prevalence data from Centrelink from 2005 relating to autism and Asperger’s Syndrome. These estimates are contained in Table 10.

Table 10 Centrelink ASD prevalence estimates from MacDermott (2007) report

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>0-5 years</th>
<th>6-12 years</th>
<th>13-16 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism</td>
<td>20.3</td>
<td>47.2</td>
<td>24.2</td>
</tr>
<tr>
<td>Asperger’s Syndrome</td>
<td>1.7</td>
<td>15.3</td>
<td>12.7</td>
</tr>
<tr>
<td>Total</td>
<td>22.0</td>
<td>62.5</td>
<td>36.9</td>
</tr>
</tbody>
</table>


Other sources have suggested that the prevalence of autism in children is higher than has been reported in the MacDermott study, with rates of 1 in 160, 1 in 150 and even 1 in 100 being reported.126 For example, in November 2009, the Queensland Education Department released its figures regarding ASD diagnoses over the past year, with the figures showing that 9,978 of 484,615 students had been diagnosed with ASD.127

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. 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. A 2006 US study by the Autism and Developmental Disabilities Monitoring Network suggests that the prevalence rate of ASD is approaching 1%, with most sites identifying prevalence of 7.5 to 10.4 cases per 1,000 children aged eight years (this was a significant increase from the Network's 2002 study).

A 2010 paper by Leonard et al notes the increase in the diagnosis of ASD across the western world, “which can be in part explained by changing diagnostic criteria, changing diagnostic practices, the introduction of diagnosis-driven funding and improved community acceptance.” One of the key issues for research is understanding how many children diagnosed with ASD would have been given an alternative diagnosis in the past, and how much of the increase in reported prevalence is a real increase in ASD.

### 5.2.2 Comorbid conditions

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.

The types of comorbid conditions that can be associated with autism include: intellectual disability, mental health problems, major depressive disorder, obsessive-compulsive disorder, epilepsy and Tuberous Sclerosis Complex.

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5.3 Early intervention strategies

Behavioural intervention is the most commonly applied form of early intervention for children with autism. This approach is based on the theory that children are capable of learning new skills by modification of stimuli and the presentation of reinforcement and involves a multi-disciplined team of specialists including speech pathologists, occupational therapists, behavioural therapists and teachers. Behavioural intervention can be provided at varying levels of intensity. The majority of research conducted on the outcomes achieved by children with autism that have received early intervention focuses on this approach.

Alternative early intervention approaches for children with autism include:

- Applied Behaviour Analysis (ABA) – this approach applies the principals of behaviour to achieve improvements in specific behaviours, most commonly through the use of discrete-trial training techniques (e.g. stimulus initiated by an adult, response from the child, and a consequence, reward or correction);

- naturalistic/developmental approaches – uses the development of relationships as the foundation for addressing behavioural impairments;

- Development Social-Pragmatic Model – this approach emphasises the importance of initiation and spontaneity in communication and follows the child’s attentional focus and motivations in an attempt to built on the child’s communicative repertoire;

- Development Individual-Difference, Relationship-Based Model – approach based on developmental interaction theory, involving more child-directed interactions in a low stimulus environment;

- Relationship Development Intervention – the objective of this technique is to develop the child’s interest and competence in developing and maintaining social relationships;

- learning experiences programs which are primarily developmentally based, with a key feature being peer-based intervention involving the integration of children with and without autism in a classroom setting;

- communications therapies focusing on developing communication skills; and

- sensory/motor therapies including sensory integration, which is aimed at developing adaptive and functional responses to sensory stimuli and auditory integration training, which focuses on hearing distortions or sensory processing anomalies.
The Commonwealth Government’s best practice guidelines for the provision of early intervention services to children with autism are set out in the box below. The content in these guidelines is consistent with the behavioural intervention strategy. As this is the most common form of early intervention for children with autism, the literature review of the benefits from early intervention has focused on this strategy.

### Box 2  Best Practice guidelines for the provision of EI services to children with autism

1. **Preparation**
   On entering an EI program, all children should have had a comprehensive, multidisciplinary diagnostic assessment from an interdisciplinary team, with the assessment being based on agreed criteria. These evaluations should include interviews with parents and caregivers, the collection of information from all professionals involved in the care of the child, and paediatric, psychological and speech pathology examinations.

2. **Timing**
   Intervention should begin as early as possible in the child’s life (optimally between 2 and 4 years).

3. **Process**
   All children should have an individual plan for their education to be developed in consultation with parents and reviewed regularly in light of the child’s progress and ongoing needs.

4. **Intensity**
   A program needs to be of at least 20 hours per week over an extended period of at least two years, with continuing support into and through the school age years.

5. **Content and focus**
   Programs need to involve autism-specific content, including:
   - Teaching joint attention skills, play, and imitation skills;
   - Building functional communication skills through language and alternative and augmentative communication;
   - Teaching social interaction skills in a supported environment;
   - Daily living skills;
   - Management of sensory issues;
   - Generalisation of learning strategies to new situations and with new people; and
   - Management of undesirable or challenging behaviours.

6. **Settings**
   Programs can be delivered in various settings, both individually and with peers. Both centre-based and individual or home-based interventions are valuable. Including typically developing peers for at least a part of the program is desirable however peer interaction must be supported.

7. **Program design and methods**
   Programs must be highly structured (well organised and focused on specific objectives). A supportive teaching environment is crucial to maximising learning. Centre-based programs require a low child/staff ratio with a maximum of 2-4 children per adult.

8. **Problem behaviours**
   A functional approach to problem behaviours including positive behaviour support which includes teaching alternative appropriate skills and communication skills to replace the problem behaviours.

9. **Staffing**

Teachers, therapists and child-care personnel should be specifically trained in working with children with autism, and possess the knowledge and skills required for their special needs.

10. Family collaboration
Parents require information about autism and services, particularly at key times such as first diagnosis and school entry. Programs need to include parent involvement, such as providing parent education services. Families are often in need of respite care. The reliable provision of this service is essential to decreasing family burden and stress.

11. Associated therapies
Multidisciplinary collaborative teams including specialist support such as speech therapy, occupational therapy and counselling should be available as needed.

12. Research and evaluation of program
Outcome evaluations should be built into programs using systematic assessments of a child’s social, cognitive, and adaptive functioning before, during, and at the end of the program.

13. Transition
There should be systematic connection and integration between the program and the next stage for the child, whether it is transition to a school or to another special educational setting. This needs to be a collaborative process involving parents, teachers and therapists.


5.4 Costs of early intervention
The cost of providing early intervention services to children with autism varies depending on the nature and intensity of the early intervention provided. Based on consultation with a major service provider, a reasonable estimate for the provision of early intervention services under an intensive behavioural intervention approach (as is consistent with the best practice guidelines) is approximately $43,000 per child per annum, with each child undergoing two years of early intervention therapy (i.e. a total per child cost of $86,000). The majority of these costs (i.e. approximately 80%) are attributable to salaries for speech pathologists, behavioural therapists, occupational therapists and other staff.

We have not discounted these costs over the two years. This is a conservative assumption (and recognises that there may be other costs that we have not captured).

We recognise that different programs involve different costs. This estimate should therefore be considered indicative only.

5.5 Benefits of early intervention
There is extensive literature on the benefits of early intervention for children with autism, which is summarised in Appendix B. It is important to note, however, that most of this evidence is based on outcomes in the short to medium-term. While these studies provide a reasonable evidence base for the benefits of early intervention for
children with autism, they are not sufficiently robust to enable long-term outcomes to be determined.

In the absence of robust outcomes studies, we can only hypothesise as to the possible long-term impacts of early intervention. The outcomes can also be expected to vary between individuals, recognising the spectrum nature of the disorder, the impact of environmental factors and also differences in individuals’ responses to early intervention. However, based on the evidence base that is available, achieving positive long-term outcomes from early intervention for individuals with autism is considered plausible, noting that studies assessing the longer term benefits of early intervention would further strengthen the evidence base.

The following sections examine the potential economic benefits that can be achieved as a result of early intervention.

5.5.1 Education

Base case

Outcomes studies for individuals with autism have revealed that a high proportion receive special education services. Three of these studies include:

- Howlin et al, which found that over 80% of a group of 68 individuals with autism attended special education institutions;\textsuperscript{132}

- Kobayashi, Murata and Yoshinaga, which found that approximately 70% of a sample population of children with autism were attending a special education institution at age 12;\textsuperscript{133} and

- Mawhood, Howlin and Rutter, which found that approximately 90% of a group of 19 males with autism had received special education services.

Based on these outcome studies, it is concluded that it is highly likely that a child with autism may require access to special education services.

Economy-wide cost estimates

The annual cost of providing special education services to children with autism was estimated in a report by Synergies on the economic costs of ASD in Australia. As at


December 2010, the range for these costs was estimated at between $116 million using low prevalence data and $208 million using high prevalence data.\(^{134}\)

**Impact of early intervention**

Past research has found a positive link between cognitive functioning levels and education needs, with IQ levels and the probability of a child with autism being placed in mainstream education sharing a positive relationship (i.e. the higher a child’s IQ, the lower the probability that they will require special education services).\(^{135}\)

Several studies which have assessed the short to medium-term outcomes achieved by children with autism receiving early intervention have reported significant improvements in IQ scores. A summary of these studies is presented in Table 11 (a more detailed review is provided in Appendix B).

<table>
<thead>
<tr>
<th>Table 11</th>
<th>Improvements in IQ scores in children with autism resulting from early intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Source</strong></td>
<td><strong>Study details</strong></td>
</tr>
<tr>
<td>Lovaas (1987)</td>
<td>Assessed outcomes achieved by 19 children with autism from intensive behavioural intervention therapy</td>
</tr>
<tr>
<td>Swallows &amp; Graupner (1999)</td>
<td>Use of several sites to assess outcomes from early intervention treatment</td>
</tr>
<tr>
<td>Eikeseth et al (2002)</td>
<td>Comparison of intensive behavioural treatment for children with autism to intensive, eclectic special education</td>
</tr>
<tr>
<td>Remington et al (2007)</td>
<td>Study assessing benefits of intensive early intervention for 23 preschool children with autism</td>
</tr>
<tr>
<td>Eikeseth et al (2007)</td>
<td>Follow up from 2002 study on positive effects of intensive applied behaviour analytic treatment for children with autism</td>
</tr>
<tr>
<td>Perry et al (2008)</td>
<td>Outcomes of children with autism in intensive behavioural intervention program</td>
</tr>
<tr>
<td></td>
<td>332 children aged 2-7 years</td>
</tr>
</tbody>
</table>

\(^{134}\) It is important to note that these estimates included children with autism and High Functioning Autism/Asperger’s Syndrome. When higher functioning individuals were removed from the calculations, the range of estimates was reduced to $81 million to $158 million.

<table>
<thead>
<tr>
<th>Source</th>
<th>Study details</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hayward et al (2009)</td>
<td>Assessed progress of children with autism receiving intensive behavioural intervention therapy</td>
<td>Mean IQ for participants increased by 16 points, with 50% gaining over 15 IQ points</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Also improvements in visual-spatial IQ</td>
</tr>
</tbody>
</table>

It is recognised that cognitive functioning may not be the only determinant of whether the child will require special education services. However, given best practice early intervention targets all of the key areas of functioning that are affected by autism, it is considered reasonable to assume that successful outcomes achieved in an early intervention program will materially increase the likelihood that a child will be able to attend a mainstream school.

*Estimating potential benefits*

As is stated in section 3.2, the additional per person cost of providing special education services to students with disabilities is estimated at $15,367 per annum. If:

- in the absence of early intervention, a child with autism would have needed to attend a special school; and
- early intervention results in a material improvement in outcomes for that child to the point where they can attend a mainstream school with or without support;

or,

- in the absence of early intervention, a child with autism would have needed to attend a mainstream school with support; and
- early intervention results in a material improvement in outcomes for that child to the point where they can attend a mainstream school without support,

this cost is avoided and therefore represents a benefit from early intervention.

If the entire cost is avoided, over 12 years of schooling, the total benefit (in Present Value terms) is estimated at $153,000 using a discount rate of 3% (base case) and $128,800 using a discount rate of 6%.

The estimate of $153,000 is considered to be the upper bound estimate for the benefits of early intervention in relation to the reduction in special education costs. The actual benefits are likely to lie between $0 and $153,000, as rather than completely negating the need for special education services, it may be that early intervention reduces the
Intensity of special education services required (i.e. the actual annual benefit is likely to be a portion of the estimate of $15,367).

We have no data to estimate the cost savings that may be realised and in practice, this will vary for each child. In the absence of this data, we could take the mid-point (that is, assume that 50% of the costs are avoided), recognising that the actual cost savings for a child could be higher or lower than this.

There may also be other benefits for the child in attending a mainstream school that have not been captured here.

5.5.2 Improved employment outcomes

Base case

One of the key economic benefits of early intervention is the increased potential of individuals with autism to secure competitive employment in their adult life. This carries a significant economic benefit to society as the individual is contributing to overall production and no longer requires welfare payments.

In considering the potential magnitude of this benefit it is firstly necessary to establish the baseline outcome for individuals with autism that do not receive early intervention. A significant body of research exists on the outcomes achieved by adults with autism. This research indicates that individuals with typical autism have a very low chance of obtaining competitive employment (2-18%) while individuals with High Functioning Autism and Asperger’s Syndrome have a significantly greater chance (17-50%).

The ABS has estimated that the labour force participation rate for people with autism in 2009 was 34%. This compares to a participation rate of 54% for people with disabilities and 83% for people without disabilities.

Economy-wide cost estimates

In its study on the economic costs of ASD in Australia, Synergies estimated the costs relating to the inability of adults with autism to obtain competitive employment. The estimated annual cost of unemployment for individuals with ASD ranged from $1.867 billion to $3.221 billion depending on the prevalence rate adopted, with individuals with typical autism accounting for the majority of these costs.

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Impact of early intervention

There have been no longitudinal studies conducted that have specifically assessed the impact of early intervention on the employment outcomes for individuals with autism. However, it is still possible to use evidence from outcome studies based on other factors that could be expected to have a bearing on an individual’s chances of obtaining competitive employment.

One of the key indicators as to whether an individual with autism will have an increased chance of obtaining employment will be educational achievements. As outlined in section 5.5.1, early intervention has the potential to improve educational outcomes for children with autism, particularly by improvements in cognitive functioning. This is already potentially evidenced by the higher employment rates for individuals with HFA, who typically also record higher IQ scores overall (relative to individuals with autism).139

The results reported in Table 11 (see section 5.5.1) clearly indicate that intensive behavioural intervention can improve cognitive functioning in young children with autism. It would therefore be expected that these improvements would improve their ability to secure competitive employment in adulthood.

The outcomes achieved for different individuals will vary considerably across the spectrum, reflecting the variations in the nature and extent of the impairment as well as the child’s response to early intervention. Social and communication skills will also be an important influence on employment outcomes, noting that these skills are also addressed as part of comprehensive behavioural intervention programs. Also, employment outcomes are influenced by factors external to the individual.

Overall, it is important to note the limitations in the existing scientific research in relation to the longer term impacts of early intervention. While the results reported in the literature are positive in terms of the short term impacts of early intervention on IQ and other indicators of cognitive functioning, there is currently no evidence that confirms that these benefits are maintained into adult life and actually translate to an improved chance of obtaining competitive employment.

Estimating potential benefits

Based on the studies that have assessed adult outcomes and the ABS data, in the absence of early intervention it is less likely that an individual with autism will be

139 Outcomes studies have shown that individuals with High Functioning Autism and Asperger’s Syndrome achieve significantly higher rates of employment compared to individuals with typical autism (17-50% as opposed to 2-18%).
capable of obtaining competitive employment compared to an individual without a disability. The majority of individuals with autism are either unemployed or are in sheltered employment.

Section 3.3 contains the estimates and parameters used to estimate the productivity benefits associated with improved employment outcomes from early intervention. The assumptions applied to full-time employment are:

- based on ABS average weekly earnings data, average annual earnings for all employees of $53,040 ($65,052 for males and $41,600 for females); and

- based on the parameters in section 3.3, a lifetime estimate for total earnings across all employees (in Present Value terms) of $1.14 million ($1.398 million for males and $0.894 million for females).

In the event that early intervention enables an individual to obtain part-time employment at the ABS rate for average annual earnings, the corresponding estimates are as follows:

- average annual earnings for all employees of $33,150 ($40,658 for males and $26,000 females). We have based this on 62.5% of full-time earnings; and

- lifetime estimate for total earnings across all employees (in Present Value terms) of $712,000 ($874,000 for males and $559,000 for females).

It is accepted that early intervention may not necessarily enable all individuals with autism to obtain employment at a rate (salary) that is commensurate with the entire population. At minimum, a person’s salary (in competitive employment) will be based on the minimum wage. The benefit associated with this outcome, as per section 3.3, is $30,644 per annum or $0.658 million in Present Value terms over a 35 year working life. The corresponding estimates for part-time employment at the minimum wage are $19,153 per annum or $412,000 over a 35 year working life.

These estimates represent the benefit that will be achieved if early intervention enables an individual with autism (who would otherwise have been unemployed) to obtain competitive employment. They can also be used to estimate the benefits of reducing underemployment, for example, where a person who would have otherwise only earned the minimum wage can secure a job at the average wage.

The table below presents the annual and lifetime benefits relating to gains in productivity as discussed above. We have also shown the sensitivity of the lifetime benefit estimates to a 6% discount rate instead of our base case assumption of 3%.
Based on these estimates, at minimum, if a person obtains competitive employment as a consequence of improved outcomes achieved as a direct result of early intervention, this could increase economic productivity by $412,000 over their working lifetime (based on part-time employment at the minimum wage). A more optimistic assumption is that they gain full-time employment at the average wage, which would result in an increase in economic productivity of $1.14 million. They may secure employment at a rate above the average wage.

As outlined above, we can also use these estimates to measure the potential benefits of reducing underemployment. For example, if a person who would have otherwise only earned the minimum wage can secure a job at the average wage, the productivity benefit will be based on the difference between their earnings based on the average wage and their earnings based on the minimum wage.

As discussed in section 3.3, there are a number of important qualifications to this approach. In particular, it assumes that the employment of the person results in a net increase in productivity in the economy, which equates to their salary.

As outlined above, the actual outcomes will vary anywhere along this spectrum. Some people with autism who have been through an early intervention program may still not gain competitive employment. However, the life outcomes for these individuals and their families may still be improved in other areas.

### 5.5.3 Improved living independence

**Base case**

Evidence from the literature indicates that, in most cases, individuals with autism do require informal or formal care, however the degree to which this is required varies significantly between individuals and across the spectrum of the disorder. Examples of study findings that support this conclusion include:
• an adult outcomes study by Howlin et al found that 72% of individuals with autism were unable to function independently in terms of basic living skills;\textsuperscript{140}

• Seltzer et al concluded that the majority of individuals with autism remained dependent on their families or professional service providers for assistance with tasks of daily living;\textsuperscript{141} and

• in a study of 450 patients with ASD in the United Kingdom, Barnard et al reported that, according to parents, 70% of the individuals with ASD could not function independently without support.\textsuperscript{142}

While the outcomes reported in studies on individuals with HFA and Asperger’s Syndrome in relation to living independence and informal care are more varied, there are still cases where the proportion of individuals living independently without care is extremely low. For example, Barnard et al reported that only 3% of the individuals with Asperger’s Syndrome were living independently.\textsuperscript{143}

\textit{Economy-wide cost estimates}

Synergies’ 2010 report on the economic costs of ASD included estimates for the cost of both formal service provision (accommodation support, community support and access, respite, and employment) and informal care.

In relation to formal services, the total annual cost of services provided to individuals with ASD was estimated at $316 million, with accommodation support accounting for approximately 50% of total expenditure. This estimate was limited to services provided under the Commonwealth State/Territory Disability Agreement and the National Disability Agreement for 2008/09 and is therefore likely to represent a conservative estimate of total costs.

In relation to informal care, the annual cost estimates ranged from $1.45 billion to $2.71 billion.\textsuperscript{144} Both the replacement method and opportunity cost method were employed to produce these estimates (refer section 3.3).


\textsuperscript{144} This range was produced using three alternative methods (two of which were based on the opportunity cost method but employed different assumptions while the third was based on the replacement cost method).
Impact of early intervention

As previously stated, no long-term studies have been undertaken assessing the impact of early intervention on adult outcomes for individuals with autism. This represents a significant barrier to quantifying the potential benefits of early intervention as it is not possible to assess an individual’s ability to live independently in adulthood.

Having noted this limitation, it is still considered appropriate to provide estimates around the potential for early intervention to improve living independence as we consider that based on the outcomes that have been reported in the literature, it is reasonable to expect that early intervention could positively impact this, at least for some people.145

Estimating potential benefits

The benefits of improvements in living independence could manifest in one or both of the following:

- reduction in the cost associated with formal services provided (i.e. accommodation support, community access and support, respite care, etc.); and/or
- reduction in informal care required.

Formal care

The estimated cost of providing formal care services to individuals with disabilities (per person per year), as well as the estimated lifetime costs, is provided in Table 13. Again, we have estimated the lifetime benefits assuming discount rates of 3% (base case) and 6%.

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145 See Appendix B for further information on the positive outcomes reported in the short to medium-term studies on early intervention for children with autism.
As the above table shows, to the extent that a person with autism is a consistent user of formal care services, and early intervention reduces their need for these services, the benefits could be up to $1.55 million. Caution must be exercised in making any generalisations from this data, however, given the nature and extent of service use and outcomes achieved will vary between individuals. For example, for some individuals who have received early intervention, they may still need to rely on formal services, however the intensity of their service use may be reduced, which would still yield a cost saving.

**Informal care**

As has been discussed in section 3.3, we are applying two approaches to estimating the costs of informal care – the opportunity cost method and the replacement cost method. In the absence of any specific data on the impact of early intervention on informal care, we can only hypothesise on possible outcomes. For example, the following table identifies three scenarios, ranging from a small reduction to a significant reduction, and shows the cost impact under each approach.

<table>
<thead>
<tr>
<th>Improvement scenario</th>
<th>Opportunity cost approach</th>
<th>Replacement cost approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small (e.g. reduction of 5 hrs of informal care per week)</td>
<td>Will not necessarily improve carer’s ability to maintain employment</td>
<td>Reduction of 5 hours of informal care required</td>
</tr>
<tr>
<td>Moderate (e.g. reduction of 15 hours of informal care per week)</td>
<td>Carer may be able to secure a part time job</td>
<td>Reduction of 15 hours of informal care required</td>
</tr>
<tr>
<td>Significant (e.g. reduction of 30 hours of informal care per week)</td>
<td>Carer may be able to secure full-time job</td>
<td>Reduction of 30 hours of informal care required</td>
</tr>
</tbody>
</table>

---

**Table 13  Per person expenditure on disability support services**

<table>
<thead>
<tr>
<th>Service</th>
<th>Annual cost ($/person)</th>
<th>Cost over 20 yrs @ 3%</th>
<th>Cost over 40 yrs @ 3%</th>
<th>Cost over 20 yrs @ 6%</th>
<th>Cost over 40 yrs @ 6%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accommodation support</td>
<td>67,101</td>
<td>998,300</td>
<td>1,551,000</td>
<td>769,600</td>
<td>1,009,600</td>
</tr>
<tr>
<td>Community support</td>
<td>6,740</td>
<td>100,300</td>
<td>155,800</td>
<td>77,300</td>
<td>101,400</td>
</tr>
<tr>
<td>Community access</td>
<td>11,429</td>
<td>170,000</td>
<td>264,200</td>
<td>131,100</td>
<td>172,000</td>
</tr>
<tr>
<td>Respite</td>
<td>9,937</td>
<td>147,800</td>
<td>229,700</td>
<td>114,000</td>
<td>149,500</td>
</tr>
<tr>
<td>Employment</td>
<td>5,469</td>
<td>81,400</td>
<td>126,400</td>
<td>62,700</td>
<td>82,300</td>
</tr>
</tbody>
</table>

**Note:** Data does not cover all expenditure on services by people with disabilities – only relates to services funded under the CSTDA and National Disability Agreement.

**Source:** Australian Institute of Health and Welfare (2011). Disability support services 2009-10. Report on services provided under the National Disability Agreement.
As can be seen from the above table, the potential benefits attributable to early intervention will vary significantly depending on the approach that is adopted. For example, consider the scenario in which the amount of informal care required is reduced by five hours per week as a result of early intervention. Under the opportunity cost approach, this would not result in any benefits being estimated due to the absence of a productivity impact, as reducing the amount of informal care provided by only five hours per week is unlikely to allow the carer to obtain employment, even on a part-time basis. Alternatively, under the replacement cost approach, the benefit will be equal to the imputed market rate for informal care multiplied by five hours per week.

The assumptions to be applied to estimate the benefits from reduced informal care (refer section 3.3) are as follows:

- opportunity cost approach: average weekly earnings of $944 or $49,105 per annum for full time employment and $30,691 for part time employment (part time estimate based on 25 hours per week); and
- replacement cost approach: a value of $31.81 per hour of care.

The table below takes the three potential improvement scenarios from Table 14 and estimates the annual benefit per person resulting from early intervention under the two approaches.

<table>
<thead>
<tr>
<th>Improvement scenario</th>
<th>Opportunity cost approach</th>
<th>Replacement cost approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small (5 hr/week reduction)</td>
<td>-</td>
<td>$8,300</td>
</tr>
<tr>
<td>Moderate (15 hr/week reduction)</td>
<td>$30,700*</td>
<td>$24,800</td>
</tr>
<tr>
<td>Significant (30 hr/week reduction)</td>
<td>$49,100</td>
<td>$49,600</td>
</tr>
</tbody>
</table>

* This estimate is based on an individual with a part time job working 25 hours per week (i.e. 62.5% of the estimate for full time employment).

Over a 35 year working life, the total benefits (in Present Value terms) are as follows:

- under the opportunity cost approach:
  - $659,700 from a moderate reduction in informal care requirements ($445,100 using a discount rate of 6%); and
  - $1.055 million from a significant reduction in informal care requirements ($711,900 using a discount rate of 6%);
• under the replacement cost approach:
  - $177,700 from a small reduction in informal care requirements ($119,900 using a discount rate of 6%); 
  - $533,100 from a moderate reduction in informal care requirements ($359,700 using a discount rate of 6%); and 
  - $1.066 million from a significant reduction in informal care requirements ($719,400 using a discount rate of 6%).

The results presented above demonstrate the wide range of potential benefits resulting from a reduction in informal care through early intervention. Even if the benefits lie between the small and moderate scenarios, the benefits are still potentially significant (recognising the other benefits that could also arise that are not captured here, such as an improvement in the carer’s own well-being).

5.5.4 Improved quality of life

Base case

As previously stated in section 3.6, the focus of this study in terms of assessing quality of life impacts has been limited to YLD (that is, we have not considered mortality). For autism, this is measured based on a disability weighting of 0.55 (see Table 3). This disability weighting is then applied to the estimate for the VOLY of $288,965 (June 2011 dollars) to produce an annual per person cost of $158,931. This estimate represents the base case cost of the reduction in quality of life for a person with autism per annum.

Economy-wide cost estimates

Synergies’ updated study on the economic costs of ASD included an estimate for the annual cost associated with the impact of autism on quality of life in Australia. The estimates used were 13,576 years and 110 years for YLD and YLL accordingly. Combining these estimates with the population estimates for individuals with autism resulted in an annual estimate of $3.91 billion (December 2010 dollars).

Impact of early intervention

The impact of a disability on quality of life is determined by a range of factors including physical and mental health issues, living independence, mobility, etc. While the lack of longitudinal studies assessing the impact of early intervention on these factors for individuals with autism constrains the ability to quantify the improvement in quality of life, there is still evidence available from short to medium-term outcome studies that indicate that early intervention is likely to improve quality of life in the
long-term and therefore achieve some benefits. These benefits can be estimated by applying reductions to the disability weighting (which outlined in section 3.6.1, represents the portion of a year of healthy life lost due to disability), which is then applied to the VOLY in order to value the improvement in quality of life per annum.

Estimating potential benefits

In the absence of any robust data linking early intervention to long-term improvements in the quality of life for individuals with autism, we can only hypothesise the benefits based on possible scenarios. Three reductions were applied to the disability weighting of 0.55 to assess the potential benefits of early intervention in terms of quality of life – a conservative reduction of 0.055 (10%), a significant reduction of 0.165 (30%) and a mid-point estimate of 0.11 (20%). There is no evidence available to support the percentage reductions. The intention is to show what the benefit might be if such improvements were realised.

These reductions were applied to the VOLY ($288,965) to derive an estimate of the annual benefit. The annual per person benefits estimated were as follows:

- $15,893 under the conservative scenario
- $31,786 under the median (or mid-point) scenario
- $47,679 under the significant improvement scenario.

A present value of the lifetime outcomes is also estimated over 20 and 40 years of adult life, using discount rates of 3% (base case) and 6%, as shown in the following table.

<table>
<thead>
<tr>
<th>Improvement scenario</th>
<th>20-year benefit</th>
<th>40-year benefit</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>3% disc. rate</td>
<td>6% disc. rate</td>
</tr>
<tr>
<td>Conservative</td>
<td>236,400</td>
<td>182,300</td>
</tr>
<tr>
<td>Median</td>
<td>472,900</td>
<td>364,600</td>
</tr>
<tr>
<td>Significant</td>
<td>709,300</td>
<td>546,900</td>
</tr>
</tbody>
</table>

Based on the scenarios modelled above, the conservative scenario of a 10% reduction in the disability weighting for 20 years of adult life produces a present value benefit of $236,400. A more optimistic scenario could yield benefits of $709,300 over the same

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146 The benefits of early intervention for individuals with autism are discussed in detail in Appendix B. The benefits that are relevant to improvements in quality of life include improvements in cognitive and adaptive functioning, communication skills and socialisation, language comprehensive and expression, motor skills and daily living skills.
time period. The longer these improvements are maintained throughout adult life, the higher the benefits.

This shows that if even small improvements are achieved (and sustained for some period), the benefits are significant. Recognising the issues involved in reliably measuring quality of life impacts, even small improvements in this metric alone could far outweigh the cost of early intervention.

### 5.5.5 Improved health outcomes

#### Base case

Synergies assessed the healthcare costs incurred by individuals with autism as part of its 2010 updated study on the economic costs of ASD. This study estimated the incremental cost of healthcare services provided to a person with ASD at $12,202 per annum. Medications and medical services accounted for the majority of this estimate (almost 80%) with other costs including hospital services, services provided by other health practitioners and patient transport services.

#### Economy-wide cost estimates

Synergies’ report also estimated the annual economy-wide cost of additional healthcare services provided to individuals with ASD in Australia in 2010. These estimates were generated by applying the low and high prevalence assumptions to the per person estimate stated above. This produced a range for the total additional healthcare costs attributable to ASD of $1.02 billion to $1.72 billion per annum.

#### Impact of early intervention

None of the studies conducted to date have assessed the impact of early intervention services on health outcomes. Despite the plausibility of improvements in outcomes in a number of key areas, we do not consider that we have a sufficient evidence base to draw a direct linkage between early intervention and health care outcomes. Accordingly, we have not sought to ascribe any benefits here.

### 5.5.6 Improved quality of life for families

There is considerable evidence suggesting that caring for a child or adult with autism has a significant impact on the family. While some of the costs associated with this impact are accounted for under the costs of informal care, there are also other costs including the impacts of higher levels of stress in the family environment (e.g. marital breakdown). Some of the evidence of the impact of autism on families includes:
a ten year longitudinal study by Gray reported that over half of the parents experienced higher levels of stress, anxiety and depression as a result of the symptoms and behaviour of a family member with autism, with approximately one-third receiving medication or psychotherapy for their condition;\textsuperscript{147}

a study by Higgins, Bailey and Pearce reported that family members of individuals with autism acknowledged the higher level of stress on families, with 41\% reporting some form of physical, emotional, financial or marital relationship stress and 25\% describing a negative effect on family life;\textsuperscript{148} and

Warfield reported that mothers of children with ASD have higher stress levels, with almost half estimated to be in the ‘critical’ range.\textsuperscript{149}

As previously stated in section 3.7, there is currently no accepted methodology available for estimating these costs and as a result they have not been included in this study. We also consider it reasonable to assume that early intervention has the potential to generate significant and positive benefits for families. Accordingly, while these benefits cannot be directly valued they should not be ignored.

5.6 Summary of benefits from early intervention

In summarising the results of this assessment it is firstly necessary to reiterate the absence of robust data on long-term outcomes for individuals with autism that receive early intervention. However, there is a considerable body of evidence in relation to the short to medium-term benefits from early intervention which forms a reasonable basis for concluding that early intervention does have the potential to generate material long-term benefits. In particular, short-term studies have demonstrated that early intervention can improve cognitive functioning and adaptive capabilities in children with autism.

The benefits of early intervention are also likely to vary considerably between children with autism. These benefits are subject to a number of factors, including:

- the nature and extent of the child’s impairments before intervention
- their age of referral to an intervention program


• the nature and intensity of the intervention received
• the child’s response to the intervention
• the influence of other environmental and contextual factors
• the presence and influence of comorbid conditions.

In assessing the potential benefits from early intervention it is also important to recognise the heterogeneous nature of the disability in terms of the nature of the individual’s impairments. The specific nature of these impairments (i.e. cognitive, language development, social functioning, adaptive functioning, etc.) will have a significant impact on the benefits of early intervention for a child with autism.

Accordingly it is not appropriate to provide point estimates of the total benefits or even a potential range of outcomes. The ability to provide such estimates would be improved by robust long-term outcome studies as this would provide evidence in relation to the early intervention strategies that work best for children with autism under particular conditions.

In section 9 we hypothesise a range of potential scenarios for a child with a disability that has received early intervention. This recognises the wide spectrum of outcomes that could be observed between different disabilities and for any group of children with the same disability (noting that this is particularly relevant for autism). We also recognise that the costs of early intervention can vary according to the nature of the program and the needs of the child and the family.

These scenarios hypothesise different combinations of outcomes, recognising that the outcome achieved in each area must be referenced to the outcomes that the child would otherwise have achieved in the absence of early intervention. Any one of these outcomes is considered plausible for a child with autism, having regard to the variables listed above. However, we cannot ascribe any probabilities to any of these scenarios being achieved.

Overall, this shows that early intervention for children with autism has the potential to generate significant positive economic benefits, recognising the variability of outcomes across the spectrum of the disability. Apart from the fact that this does not capture the full spectrum of outcomes that may be achievable, it is also important to remember that there are also other benefits that have not been quantified, such as improvements in the quality of life for families. Those benefits alone may be material.
6  Cerebral Palsy

6.1  Overview of the disability

6.1.1  Functional definition and causes

Cerebral Palsy is defined as a group of permanent disorders of the development of movement and posture causing activity limitation that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of Cerebral Palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems.\(^{150}\)

It is estimated that 5 to 10% of cases of Cerebral Palsy are due to postnatal events such as infections (33%), accidental head injury (16%), stroke (7%), medical interventions (20%) or other causes (20%).\(^{151}\) The vast majority of cases of Cerebral Palsy (90 to 95%) are due to brain injury occurring before one month of age, either antenatally (in utero, e.g. maternal infection, blood clot), perinatally (at the time of delivery, e.g. lack of oxygen during birth) or during the neonatal period (in the first 28 days of life, e.g. a brain bleed or stroke associated with prematurity).

The Australian Cerebral Palsy Register (ACPR) indicates that infants most at risk are:\(^{152}\)

- males – at greater risk of having Cerebral Palsy relative to females;
- premature babies – 42% of children with Cerebral Palsy in Australia are born prematurely compared to 8% of the total population;
- small babies – low birth weight is associated with higher rates of Cerebral Palsy, potentially due to prematurity of slow intrauterine growth. Approximately 43% of children with Cerebral Palsy had low birth weight compared to just over 6% of the total population; and
- twins, triplets and higher multiple births – 11% of children with Cerebral Palsy were from a multiple birth, whereas the rate of multiple births is only 1.7% across the total population.


\(^{152}\) ACPR Group(2009).
Although the brain injury causing Cerebral Palsy is permanent and non-progressive, the associated sensory, motor and neurological impairments may result in significant progression of functional limitations and secondary musculoskeletal impairments over time. The result is that there are varying degrees of participation restrictions observed in individuals with Cerebral Palsy in relation to functional mobility, daily living skills, and communication and socialisation skills.153

6.1.2 Classifications of Cerebral Palsy

Cerebral Palsy is a heterogeneous disability, both between individuals and in terms of the severity of different aspects of the disability within individuals. To ensure a common understanding between clients and service providers, the international standard is to describe a person’s abilities using classification systems that quantify specific aspects of the disability, with each system comprising a five point scale from most mild to most severe. To date, three main classification systems have been developed and validated for this population. These systems are as follows:

- Gross Motor Function Classification System (GMFCS) – based on self-initiated movement, with emphasis on sitting, transfers, and mobility. The distinctions across the five levels are based on functional limitations, the need for hand-held mobility devices or wheeled mobility and quality of movement;154
- Manual Abilities Classification System (MACS) – based on a child’s ability to handle objects in important daily activities, for example during play and leisure, eating and dressing;155 and
- communication, which can be scored using either the Functional Communication Classification System (FCCS) or Communication Function Classification System (CFCS)156 based on how a child communicates in their daily lives.157

Table 17 provides an overview of the criteria applied under these three classification systems to describe the severity of Cerebral Palsy for each individual. Other aspects of

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156 The CFCS is yet to be published and is currently in limited use. The Surveillance of Cerebral Palsy in Europe (SCPE) is currently undertaking a research project to determine which system to implement.
a person’s Cerebral Palsy can be quantified using standard scales (e.g. intelligence quotient) or test ranges (e.g. oral motor function, tactile function, hearing, vision).

### Table 17 Criteria for different levels of severity of Cerebral Palsy under different classification systems

<table>
<thead>
<tr>
<th>Classification system</th>
<th>Level I</th>
<th>Level II</th>
<th>Level III</th>
<th>Level IV</th>
<th>Level V</th>
</tr>
</thead>
<tbody>
<tr>
<td>GMFCS</td>
<td>Walks without limitations</td>
<td>Walks with limitations</td>
<td>Walks with a handheld mobility device</td>
<td>Self-mobility with limitations; may use powered mobility</td>
<td>Transported in manual wheelchair</td>
</tr>
<tr>
<td>MACS</td>
<td>Handles objects easily and successfully</td>
<td>Handles most objects but with somewhat reduced quality and/or speed of achievement</td>
<td>Handles objects with difficulty; needs help to prepare and/or modify activities</td>
<td>Handles a limited selection of easily managed objects in adapted situations</td>
<td>Does not handle objects and has severely limited ability to perform even simple actions</td>
</tr>
<tr>
<td>FCCS</td>
<td>An effective communicator in most situations</td>
<td>An effective communicator in most situations, but does need some help</td>
<td>An effective communicator in some situations. Can communicate a small range of messages/topics to most familiar people</td>
<td>Assistance is required in most situations, especially with unfamiliar people and environments. Communicates daily/routine needs and wants with familiar people</td>
<td>Communicates unintentionally with others, using movement and behaviour</td>
</tr>
</tbody>
</table>

These classification systems demonstrate the wide spectrum of activity limitations experienced by people with Cerebral Palsy. A person may have severe impairments in one or more areas but only minor impairments in others. Others may be severely impaired in all key functional areas. Some people will be only mildly affected but may still need some form of assistance. This therefore means that the needs of people with Cerebral Palsy will be many and varied.

### 6.1.3 Recent prevalence estimates

As part of its 2007 study on the economic impact of Cerebral Palsy, Access Economics estimated the prevalence of Cerebral Palsy in Australia. Based on an assessment of available data, it was estimated that 0.2% of the population had been diagnosed with Cerebral Palsy and that this proportion had been relatively stable over a number of years.158 This is consistent with a 2009 report on the ACPR, which estimated a prevalence of 2 per 1,000 live births. The report also estimated that approximately 95% of cases were caused by brain injury during the prenatal and perinatal period of infant development.159

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Based on Australia’s current population (estimated by the ABS at 22,817,444 as of 30 January 2012) and an assumed prevalence of Cerebral Palsy of 2 per 1000 live births, it is estimated that 45,635 people in Australia have Cerebral Palsy.

6.1.4 Comorbid conditions

The 2009 ACPR report indicates that a number of associated impairments occur frequently in children with Cerebral Palsy, with 50% having more than one associated impairment:

- 31% have epilepsy;
- 45% have an intellectual impairment, with 22% of those having a moderate, severe or profound intellectual impairment;
- 60% have a speech impairment, with 27% of those being non-verbal;
- 47% have a vision impairment, with 5% of those being functionally blind; and
- 12% have a hearing impairment, with 3% of those having bilateral deafness.\(^{160}\)

6.2 Early intervention strategies

6.2.1 Allied health interventions

Early intervention treatments are used to improve outcomes in children with neurological conditions such as Cerebral Palsy because of its potential effectiveness in developing the child’s brain to better cope with the disability in the first few years of life (while the brain is still developing).

The type of early intervention (i.e. service delivery model, intensity, duration, environment, etc.) that is administered to children with Cerebral Palsy will vary depending on the symptoms that are experienced by the child. Due to the spectrum nature of the disability, it is necessary for early intervention programs to be tailored to meet the specific needs of each child.

There are five key types of allied health therapy interventions that are provided to children with Cerebral Palsy under early intervention programs:

- physiotherapy – aimed at improving and maintaining each child’s neuro-sensory-motor function for optimal posture and movement, by:

\(^{160}\) ACPR Group (2009).
- manual/exercise therapies, e.g. facilitation and handling, strength training, postural control training, gait training, activities that promote increased range of motion, serial casting; and
- prescription of assistive technology, e.g. those that aid mobility (e.g. orthotics, walking aids and wheelchairs) and positioning (e.g. standing frames and custom seating);

- occupational therapy - emphasis on improving independence, personal productivity, well-being and quality of life, most specifically by focusing on arm use and self care skills. Occupational therapists also address cognitive and perceptual impairments, improve the child’s ability to adapt to aides and equipment, and improve the child’s ability to adapt to different environments;

- speech-language therapy - aims to maximise the child’s ability to communicate through speech and via other methods (e.g. gestures), in addition to assisting children who have difficulties swallowing food and drink. The use of aides such as symbol cards and speech synthesisers plays an important role in therapy provided to children with Cerebral Palsy;

- psychology - provision of assistance to children and their families on a range of issues such as living with a disability, key life transitions, social and anxiety issues, parenting and behaviour management, in addition to providing specialist assessments of intellect and learning abilities;

- social work - important advocacy role played by social workers, particularly in addressing barriers and inequalities in society and providing support during times of distress or transition. Social workers place a strong focus on improving family functioning;\(^\text{161}\) and

- other specialist professionals to provide treatment for specific aspects of a child’s functioning, such as orthotists, dieticians and nutritionists, and audiologists.

Allied health professionals in the above fields can work together to provide coordinated and comprehensive early intervention for children with Cerebral Palsy.

As outlined above, due to the heterogeneous nature of the disability and the different types of impairments that can occur across the spectrum (i.e. neurological, motor, sensory, cognitive etc.) the variety of allied health services and intervention delivery

models that will be required will vary between individuals. Allied health intervention services can be provided in either:

- community venues – focusing on assisting a child’s learning and social participation capabilities; or
- centre-based venues – focusing on specific skill assessment and development.

The model under which allied health therapy services are provided will be subject to the specified goals of early intervention.

The objectives of allied health early intervention therapies are directed by the family and child-expressed support needs. These objectives focus on skill development in a variety of functional areas.\(^{162}\)

Other therapy interventions for children with Cerebral Palsy that are provided by allied health professionals include:

- neuro-developmental therapy – a forward-looking, interdisciplinary problem-solving approach to the assessment, treatment and management of any individual with limited ability to fully participate in daily life due to impairments of motor (including tone and patterns of movement), sensory, perceptual and cognitive function resulting from a central nervous system disorder\(^{163}\);
- programs based on the principles of conductive education – group programs that teach movement through verbal cueing for each aspect of a functional task where a conductor facilitates the program and parents facilitate their child’s movement and participation; and
- constrain induced movement therapy – involves constraining the child’s unaffected hand/arm for a period of time and encouraging the use of the other hand/arm in various activities with the aim of increasing the child’s use of their hemiplegic hand/arm.

## 6.2.2 Medical and surgical interventions

Medications and surgical procedures are another form of early intervention that can be provided to Cerebral Palsy. It is important to note that these interventions are provided to a small percentage of children and are limited to children with severe spasticity that interrupts physical functioning.

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\(^{163}\) European Bobath Tutors Association (2005).
For example, a commonly used form of medical intervention is intrathecal baclofen therapy. This treatment involves the implantation of a pump reservoir and a computer system under the skin of the abdomen. This is then attached to a catheter which delivers baclofen to the fluid around the spine. There is strong evidence that this treatment relieves spasticity and improves ease of care and comfort in children with Cerebral Palsy. A cost-effectiveness study found that the therapy resulted in an average gain of 1.2 quality-adjusted life years (at an additional cost of $49,000 over a five year program). Balcofen can also be used post-therapy to manage spasticity in children with Cerebral Palsy.

In terms of surgical interventions, the most common procedures performed on children with Cerebral Palsy are:

- hip surveillance;
- bone and soft tissue surgery of the upper and lower limbs; and
- early monitoring for later more complex interventions such as Selective Dorsal Rhizotomy (SDR); Single Event Multi-level Surgery (SEMLS) for the lower limbs and Spinal Surgery.

Additional information on these interventions is provided in Appendix 10C.

6.3 Costs of early intervention

A highly comprehensive assessment of the recommended costs of community services required by children and adolescents with Cerebral Palsy up to 18 years of age was provided by the Cerebral Palsy League. The estimates provided included the annual per child costs (in July 2011 dollars) across four categories:

- service options/case coordination services
- allied health services
- assistive technology - prescription, purchase and implementation
- child and family support services provided at home and in the community.

Cost estimates were also differentiated across the five severity classifications for Cerebral Palsy. Figure 4 illustrates the annual costs estimated by the Cerebral Palsy League across the five levels of severity on a per child basis. These estimates

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demonstrate that overall, the costs of services and equipment required by children with Cerebral Palsy can be very significant.

**Figure 4** Total cost of services recommended for children with Cerebral Palsy under 5 years of age (according to GMFCS, MACS or FCCS level as relevant to the service being provided)

![Graph showing total cost of services recommended for children with Cerebral Palsy under 5 years of age.](image)

**Data source:** Cerebral Palsy League.

There are additional complexities associated with estimating the cost of early intervention for Cerebral Palsy compared to the other four disabilities included in this study (Down Syndrome, ASD, hearing impairment and visual impairment). For these disabilities, we focused on therapy and support services that are specifically targeted at improving functioning in key areas.

The complex nature of Cerebral Palsy makes it more difficult to identify which costs are specific to early intervention, particularly in relation to the physical aspects of the disability. For example, for children with the most severe motor impairments (GMFCS III-V, 35% of population) equipment such as orthotics, walkers and wheelchairs are essential to achieve any type of functional mobility (noting that many hours of work also goes into having equipment properly fitted and for training the child, family and school staff how to use and maintain the equipment). Ensuring that this equipment can be accessed at an appropriately early stage in life will not only assist the child’s development and physical functioning, but can also facilitate access to other forms of intervention therapy.
6.4 Benefits of early intervention

While some studies have been conducted assessing the short to medium term impact of early intervention for children with Cerebral Palsy, the evidence base supporting its effectiveness is relatively limited. An overview of some of the literature on the benefits of early intervention for children with Cerebral Palsy is contained in Appendix C.

In the absence of robust long-term outcomes studies, we can only hypothesise as to the possible long-term impacts of early intervention. The outcomes can also be expected to vary between individuals, recognising the heterogeneity in the characteristics of each child, the impact of environmental factors and their response to intervention. However, based on the research that has been done, achieving positive long-term outcomes from early intervention for children with Cerebral Palsy is considered plausible. Further research is needed to be able to robustly identify and measure these outcomes over the longer term, including understanding which strategies work best (that is, type, intensity, frequency, timing and duration) and under what circumstances.

The following sections examine the potential economic benefits that can be achieved as a result of early intervention.

6.4.1 Education

Base case

The outcomes studies for individuals with Cerebral Palsy clearly indicate that children with Cerebral Palsy will typically require some form of special education services, either in the form of attending a special education institution or receiving additional aids and support in a mainstream school environment. This conclusion is largely based on results reported in the outcomes studies in relation to the cognitive abilities of individuals with Cerebral Palsy. Examples of these studies include:

- the Surveillance of Cerebral Palsy in Europe (SCPE), reported that the proportion of individuals with Cerebral Palsy that experience cognitive difficulties ranges from 23% to 44%. This is supported by data from the ACPR which indicates that approximately 40% of individuals with Cerebral Palsy experienced cognitive difficulties (noting that the nature of cognitive difficulties ranges from mild to profound).\(^{165}\)

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\(^{165}\) Access Economics (2008).
• Liptak and Accardo reported that approximately 50% of children with Cerebral Palsy have an intellectual disability;\textsuperscript{166} and

• Fenner and Dikel reported that, based on past reviews, estimates of the frequency of intellectual disability in individuals with Cerebral Palsy ranged from 50% to 70%.\textsuperscript{167}

Based on these outcomes, and also having consideration for the physical, social and communication problems that are often experienced by individuals with Cerebral Palsy, it is appropriate to conclude that it is highly likely that a child with Cerebral Palsy may require access to special education services whether they attend a special school or receive additional support in a mainstream setting.

\textit{Economy-wide cost estimates}

Access Economics’ study on the economic impact of Cerebral Palsy in Australia in 2007 did not include an assessment of the special education costs attributable to Cerebral Palsy.

\textit{Impact of early intervention}

Cognitive functioning levels provide some reasonable indicator as to the educational outcomes (and special education services required) for children with Cerebral Palsy, recognising that other factors, such as communication and motor skills, will also influence educational performance. Indeed improving movement and communication skills can provide an important foundation for improving cognitive development. To the extent that early intervention improves cognitive functioning in individuals with Cerebral Palsy, it can be reasonably hypothesised that this will result in a reduction in the special education services required.

While the evidence base for the impact of early intervention on the cognitive abilities of children with Cerebral Palsy is relatively limited, some studies have been conducted which demonstrate that early intervention has the potential to improve functioning at the school-aged level. For example, an outcomes study conducted by Hernandez-Reif et al found that early intervention resulted in improvements in cognition in a group of 20 children with Cerebral Palsy.\textsuperscript{168} Also, a study by King et al on the effectiveness of early intervention for a group of children with special needs (52% of which were

\begin{flushright}
\end{flushright}
diagnosed with Cerebral Palsy) found that intervention had resulted in functional improvements in communication levels and school productivity.\textsuperscript{169}

\textit{Estimating potential benefits}

We have no specific data linking early intervention for children with Cerebral Palsy to education outcomes. Accordingly, we can only hypothesise as to the possible benefits.

As is stated in section 3.2, the additional per person cost of providing special education services to students with disabilities is estimated at $15,367 per annum. If:

- in the absence of early intervention, a child with Cerebral Palsy would have needed to attend a special school; and

- early intervention results in a material improvement in outcomes for that child to the point where they can attend a mainstream school (although most likely with ongoing support, such as assistive technologies like communication and mobility devices);

or,

- in the absence of early intervention, a child with Cerebral Palsy would have needed to attend a mainstream school with support; and

- early intervention results in a material improvement in outcomes for that child to the point where those support needs are reduced,

at least part of this cost is avoided and therefore represents a benefit from early intervention. If the entire cost is avoided, over 12 years of schooling, the total benefit (in Present Value terms) is estimated at $153,000 using a discount rate of 3\% and $128,800 using a discount rate of 6\%.

This estimate is considered to be the upper bound estimate for the benefits of early intervention in relation to the reduction in special education costs. On average, the actual benefits for an individual are likely to lie between $0 and $153,000, as rather than completely negating the need for special education services, early intervention may reduce the intensity of special education services required for a child (i.e. the actual annual benefit may be some portion of the estimate of $15,367).

We have no data to estimate the cost savings that may be realised and in practice, this will vary for each child. In the absence of this data, we could take the mid-point (that

is, assume that 50% of the costs are avoided), recognising that the actual cost savings for a child could be higher or lower than this.

There may also be other benefits for the child in attending a mainstream school that have not been captured here.

### 6.4.2 Improved employment outcomes

**Base case**

The majority of past studies which have assessed the competitive employment outcomes for individuals with Cerebral Palsy have reported poor outcomes. The results of some of the more recent studies are summarised in Table 18.

<table>
<thead>
<tr>
<th>Authors</th>
<th>Year</th>
<th>Study details</th>
<th>Employment outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Murphy, Molnar &amp; Lankasky</td>
<td>2000</td>
<td>Study of 101 participants with Cerebral Palsy aged between 27 and 74 years living independently</td>
<td>53% were found to be competitively employed with 22% being in a position that an increase in income would result in financial loss due to the termination of disability benefits</td>
</tr>
<tr>
<td>Bottos, et al</td>
<td>2001</td>
<td>Study of 72 adults born with Cerebral Palsy between 1934 and 1980</td>
<td>66% of individuals for which information was provided were unemployed</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>16% in sheltered employment with 18% competitively employed</td>
</tr>
<tr>
<td>Van der Dussen, et al</td>
<td>2001</td>
<td>Study of 80 young adults with Cerebral Palsy aged between 21 and 31 years</td>
<td>53% had completed some form of secondary education with 36.3% in paid employment (compared to 73% of the general population)</td>
</tr>
<tr>
<td>Michelsen, et al</td>
<td>2005</td>
<td>Study of educational and employment outcomes of 819 adults with Cerebral Palsy in Denmark</td>
<td>29% of adults with Cerebral Palsy found to be competitively employed compared to 82% from the control group</td>
</tr>
<tr>
<td>Donkevoort, et al</td>
<td>2007</td>
<td>Study on functioning of adolescents and young adults with Cerebral Palsy in the Netherlands</td>
<td>Study found that 20-30% of adults with Cerebral Palsy had restricted social participation which included employment</td>
</tr>
</tbody>
</table>

It is clear from these studies that the employment outcomes achieved by individuals with Cerebral Palsy are significantly inferior to those achieved by the general population.

The review of the literature also indicated that, for Cerebral Palsy, cognitive ability is the most appropriate indicator of long-term employment outcomes. As was reported in section 6.4.1, there is a considerable body of evidence to show that a significant proportion of individuals with Cerebral Palsy experience cognitive difficulties. This further supports the conclusion that employment outcomes for individuals with Cerebral Palsy are relatively poor (compared to the total population), recognising that

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170 This observation was reported in both Liptak & Accardo (2004) and Murphy, Molnar & Lankasky (2000).
other factors (including contextual factors that are external to the individual) will also influence employment outcomes.

**Economy-wide cost estimates**

Access Economics' study assessed the costs associated with the loss of productivity relating to the poor employment outcomes achieved by individuals with Cerebral Palsy relative to the general population. The total cost estimate produced was $1,026.5 million. Of this total, a reduction in employment participation accounted for 52%. The other categories comprising the total were reduced productivity (23%), absenteeism (16%), and premature death (9%).

**Impact of early intervention**

Due to the lack of longitudinal studies that have assessed the impact of early intervention on the employment outcomes for individuals with Cerebral Palsy (recognising the practical difficulties in undertaking these studies, as outlined in section 2) it is again only possible to hypothesise in relation to possible outcomes and benefits.

To the extent that early intervention is able to materially improve the development path for a child with Cerebral Palsy, and therefore improve their education performance and their ability to function in different environments, it is plausible that early intervention could lead to improved employment outcomes for people with Cerebral Palsy.

As is stated in section 6.4.1, there is some evidence indicating that early intervention improves cognitive functioning and other functional abilities in children with Cerebral Palsy. As stated above, this indicates the potential for longer term benefits attributable to early intervention in the form of improved employment outcomes.

There are a number of caveats to this assumption. First, there are other aspects of functioning that will impact educational attainment and (or) employment outcomes (i.e. communication, physical capabilities, etc.). Second, the outcomes achieved for different individuals will vary, reflecting the variations in the nature and extent of the impairment as well as the child’s response to early intervention. Third, employment outcomes are influenced by factors external to the individual (e.g. employer attitudes and financial barriers).

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**Estimating potential benefits**

Section 3.3 contains the estimates and parameters used to estimate the productivity benefits associated with improved employment outcomes from early intervention. The assumptions applied to full-time employment are:

- based on ABS data, an average annual salary for all employees of $53,040 ($65,052 for males and $41,600 for females); and
- based on the parameters in section 3.3, a lifetime estimate for total earnings across all employees (in Present Value terms) of $1.14 million ($1.398 million for males and $0.894 million for females).

In the event that early intervention enables an individual to obtain part-time employment at the ABS rate for average annual earnings, the corresponding estimates are as follows:

- average annual earnings for all employees of $33,150 ($50,658 for males and $26,000 for females). We have based this on 62.5% of full-time earnings; and
- lifetime estimate for total earnings across all employees (in Present Value terms) of $712,000 ($874,000 for males and $559,000 for females) using a 3% discount rate.

It is accepted that early intervention may not necessarily enable all individuals with Cerebral Palsy to obtain employment at a rate (salary) that is commensurate with the entire population. At minimum, a person’s salary (in competitive employment) will be based on the minimum wage. The benefit associated with this outcome, as per section 3.3, is $30,644 per annum or $0.658 million in Present Value terms over a 35 year working life. The corresponding estimates for an individual that is able to secure part-time employment at the minimum wage are $19,153 per annum or $412,000 over a 35 year working life.

These estimates represent the benefit that will be achieved if early intervention enables an individual with Cerebral Palsy – who would otherwise have been unemployed – to obtain competitive employment. They can also be used to estimate the benefits of reducing underemployment, for example, where a person who would have otherwise only earned the minimum wage can secure a job at the average wage.

Table 19 presents the annual and lifetime benefits relating to gains in productivity as discussed above. We have also shown the sensitivity of the lifetime benefit estimates to a 6% discount rate instead of our base case assumption of 3%.
Based on these estimates, if a person would have otherwise been unemployed but obtains competitive employment as a consequence of improved outcomes achieved as a direct result of early intervention, this could increase economic productivity by $412,000 over their working lifetime (based on part-time employment at the minimum wage). A more optimistic assumption is that they gain full-time employment at the average wage, which would result in an increase in economic productivity of $1.14 million. They may secure employment at a rate above the average wage.

As outlined above, we can also use these estimates to measure the potential benefits of reducing underemployment. For example, if a person who would have otherwise only earned the minimum wage can secure a job at the average wage, the productivity benefit will be based on the difference between their earnings based on the average wage and their earnings based on the minimum wage.

As discussed in section 3.3, there are a number of important qualifications to this approach. In particular, it assumes that the employment of the person results in a net increase in productivity in the economy, which equates to their salary.

As outlined above, the actual outcomes will vary anywhere along this spectrum. Some people with Cerebral Palsy will have gained employment without early intervention. Others who have been through an early intervention program may still not gain competitive employment. However, the life outcomes for these individuals and their families may still be improved in other areas.

6.4.3 Improved living independence

Base case

As indicated by the literature, a variety of outcomes could be expected for people with Cerebral Palsy in terms of living independence, ranging from reliance on formal care services, to living with parents, to living in a semi-independent or fully independent
environment. The physical nature of the impairment can also increase reliance on external support. Further, a person may be able to live ‘independently’ (that is with no or limited reliance on formal or informal care), but still rely on supports such as assistive technology.

Some studies found that the rate of independent living among individuals with Cerebral Palsy was relatively high:

- Andren and Grimby found that out of 22 adults with Cerebral Palsy and 9 with Spina Bifida, 48% were living with their partners and only 10% with their parents;\(^{172}\)

- Murphy, Molnar and Lankasky reported that out of 101 adults with Cerebral Palsy, 67% were living independently, 34% with an attendant and 33% without an attendant;\(^{173}\) and

- Van der Dussen et al found that of 80 adults with Cerebral Palsy, 75% were either largely or fully independent in daily living activities, with only 30% living with their parents.\(^{174}\)

However, there is also evidence in the literature that suggests that outcomes may not be as positive as is suggested by these results. For example, in a study of 72 adults with Cerebral Palsy, Bottos et al found that only 12.5% of individuals lived independently, with 12.5% living in institutions and 75% living with their parents.\(^{175}\)

Data reported by Access Economics for its 2007 study also indicates that the level of independent living by adults with Cerebral Palsy may not be as high as is reported elsewhere in the literature. The study found that 41.5% of people with Cerebral Palsy require a carer, compared to only 2.4% of the general population. Access Economics also estimated that a weighted average\(^{176}\) of 31.4 hours of informal care was provided by primary carers to individuals with Cerebral Palsy on a weekly basis.\(^{177}\)


\(^{176}\) The weighted average was calculated based on SDAC data for the average number of hours of care provided by primary carers, with 20.2% providing less than 20 hours of care per week on average, 9.9% providing between 20 and 40 hours and 66% providing over 40 hours (the remaining 3.9% did not state the number of hours of care provided).

\(^{177}\) Access Economics (2008).
Based on the review of the outcomes literature, it is concluded that there is a wide range of outcomes for adults with Cerebral Palsy in relation to living independence, with a significant proportion requiring informal or formal care services. The physical dimension of Cerebral Palsy also means that the ability for a person to live independently will continue to require support via assistance technology (the ongoing costs of which are not within the scope of our study).

**Economy-wide cost estimates**

Access Economics estimated the value associated with the informal care provided to people with Cerebral Palsy using the opportunity cost method (i.e. the value of wages lost due to informal care). Available epidemiological data was combined with data from the ABS Survey of Disability, Ageing and Carers (SDAC) to obtain estimates for the number of hours of care provided to individuals with Cerebral Palsy and the average unit cost of that care. The SDAC identified approximately 13,400 informal carers who cared for individuals with Cerebral Palsy as their primary disability.

Based on SDAC data, Access Economics also estimates that a weighted average of 31.4 hours of informal care per week was provided by primary informal carers for individuals with Cerebral Palsy. For non-primary carers, an estimate of five hours per week was adopted. This resulted in the total opportunity cost of informal care provided to individuals with Cerebral Palsy in 2007 being estimated at $128.6 million. The removal of the $43 million transfer relating to foregone taxation revenue resulted in a reduction of the total cost estimate to $85.6 million.\(^{178}\)

**Impact of early intervention**

As previously stated, there is no robust evidence available that enables us to directly estimate the impact of early intervention for children with Cerebral Palsy on their ability to live independently as adults (recognising that the presence of physical impairments may mean that ‘living independence’ in this context still depends on the ongoing use of assistive technologies). Having noted this limitation, it is still considered appropriate to provide estimates around the potential for early intervention to produce benefits by improving living independence as we consider that such outcomes are plausible based on short term studies that have demonstrated functional improvements in children with Cerebral Palsy as a result of early intervention.\(^{179}\)

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\(^{178}\) Access Economics (2008).

\(^{179}\) For example, follow up studies conducted by King et al (2000) have found that early intervention therapy sessions were successful in improving the functioning of children with special needs in the school setting, with children showing significant improvements in mean functional status.
Estimating the potential benefits

The benefits of improvements in living independence could manifest in one or both of the following:

- reduction in the cost associated with formal services provided (i.e. accommodation support, community access and support, respite care, etc.); and/or
- reduction in informal care required.

Formal care

As stated in section 3.4.1, it has not been possible to generate estimates of the costs incurred in providing formal care services for all of the specific disabilities. However, it is possible to estimate the cost of services provided to individuals across all disabilities. It is also considered reasonable to conclude that people with Cerebral Palsy could require formal care services (dependent upon a person’s level of physical, communicative and cognitive impairment).

The estimated cost of providing formal care services to individuals with disabilities (per person per year), as well as the estimated lifetime costs, is provided in Table 20 (recalling that we do not have specific data for people with Cerebral Palsy). Again, we have estimated the lifetime benefits assuming discount rates of 3% (base case) and 6%.

Table 20  Per person expenditure on disability support services

<table>
<thead>
<tr>
<th>Service</th>
<th>Annual cost ($/person)</th>
<th>Cost over 20 yrs @ 3%</th>
<th>Cost over 40 yrs @ 3%</th>
<th>Cost over 20 yrs @ 6%</th>
<th>Cost over 40 yrs @ 6%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accommodation support</td>
<td>67,101</td>
<td>998,300</td>
<td>1,551,000</td>
<td>769,600</td>
<td>1,009,600</td>
</tr>
<tr>
<td>Community support</td>
<td>6,740</td>
<td>100,300</td>
<td>155,800</td>
<td>77,300</td>
<td>101,400</td>
</tr>
<tr>
<td>Community access</td>
<td>11,429</td>
<td>170,000</td>
<td>264,200</td>
<td>131,100</td>
<td>172,000</td>
</tr>
<tr>
<td>Respite</td>
<td>9,937</td>
<td>147,800</td>
<td>229,700</td>
<td>114,000</td>
<td>149,500</td>
</tr>
<tr>
<td>Employment support</td>
<td>5,469</td>
<td>81,400</td>
<td>126,400</td>
<td>62,700</td>
<td>82,300</td>
</tr>
</tbody>
</table>

Notes: Data does not cover all expenditure on services by people with disabilities – only relates to services funded under the CSTDA and National Disability Agreement. For presentation purposes the lifetime estimates have been rounded.


Based on the above table, to the extent that a person with Cerebral Palsy is a consistent user of formal care services, and early intervention reduces their need for these services, the benefits could be up to $1.55 million (this is the avoided cost of long-term accommodation support). Caution must be exercised in making any generalisations
from this data, however, given the nature and extent of service use and outcomes achieved will vary both between disabilities and individuals within the same disability. For example, for some individuals who have received early intervention, they may still need to rely on formal care services, however the intensity of their service use may be reduced, which would still yield a cost saving.

Informal care

In relation to informal care, as discussed in section 3.4.2, we are applying two approaches to estimating the potential benefits of early intervention in relation to the provision of informal care – the opportunity cost method and the replacement cost method. In the absence of any specific data on the impact of early intervention on informal care, we can only hypothesise on possible outcomes. For example, Table 21 identifies three scenarios, ranging from a small reduction to a significant reduction in informal care requirements, and shows the cost impact under the two approaches.

<table>
<thead>
<tr>
<th>Improvement scenario</th>
<th>Opportunity cost approach</th>
<th>Replacement cost approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small (e.g. reduction of 5 hrs of informal care per week)</td>
<td>Will not necessarily improve carer’s ability to maintain employment</td>
<td>No productivity impact</td>
</tr>
<tr>
<td>Moderate (e.g. reduction of 15 hours of informal care per week)</td>
<td>Carer may be able to secure a part-time job</td>
<td>Increase in productivity based on part-time contribution</td>
</tr>
<tr>
<td>Significant (e.g. reduction of 30 hours of informal care per week)</td>
<td>Carer may be able to secure full-time job</td>
<td>Increase in productivity based on full-time contribution</td>
</tr>
</tbody>
</table>

The above table demonstrates that the potential benefits attributable to early intervention will vary significantly depending on the approach that is adopted. For example, consider the scenario in which the amount of informal care required is reduced by five hours per week as a result of early intervention. Under the opportunity cost approach, this would not result in any benefits being estimated due to the absence of a productivity impact (as reducing the amount of informal care provided by only five hours per week is unlikely to allow the carer to obtain employment). Alternatively, under the replacement cost approach, the benefit will be equal to the imputed market rate for informal care multiplied by five hours per week.

The assumptions to be applied to estimate the benefits from reduced informal care, as
set out in section 3.4.2 are as follows:

- opportunity cost approach: average weekly earnings of $944 or $49,105 per annum for full time employment and $30,691 for part time employment (part time estimate based on 25 hours per week); and

- replacement cost approach: a value of $31.81 per hour of care.

Table 22 takes the three potential improvement scenarios from Table 21 and estimates the annual benefit per person resulting from early intervention under the two approaches.

<table>
<thead>
<tr>
<th>Improvement scenario</th>
<th>Annual benefit</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Opportunity cost approach</td>
</tr>
<tr>
<td>Small (5 hr/week reduction)</td>
<td>$8,300</td>
</tr>
<tr>
<td>Moderate (15 hr/week reduction)</td>
<td>$30,700 $30,700 x 25 hours/wk x 52 weeks/year = $30,700</td>
</tr>
<tr>
<td>Significant (30 hr/week reduction)</td>
<td>$49,100 $49,100 x 25 hours/wk x 52 weeks/year = $49,100</td>
</tr>
</tbody>
</table>

*a This estimate is based on an individual with a part time job working 25 hours per week (i.e. 62.5% of the estimate for full-time employment). Numbers have been rounded to the nearest hundred dollars.

Over a 35 year working life, the total benefits (in Present Value terms) are as follows:

- under the opportunity cost approach:
  - no benefit from a small reduction in informal care requirements;
  - $659,700 from a moderate reduction in informal care requirements ($445,100 using a discount rate of 6%); and
  - $1.055 million from a significant reduction in informal care requirements ($711,900 using a discount rate of 6%);

- under the replacement cost approach:
  - $178,300 from a small reduction in informal care requirements ($120,300 using a discount rate of 6%);
  - $532,900 from a moderate reduction in informal care requirements ($359,600 using a discount rate of 6%); and
  - $1.066 million from a significant reduction in informal care requirements ($719,100 using a discount rate of 6%).

The results presented above demonstrate the wide range of potential benefits resulting from a reduction in informal care requirements through early intervention. Even if the
benefits lie between the small and moderate scenarios, the benefits are still potentially significant, recognising the other benefits that could also arise that are not captured here, such as an improvement in the carer’s own well-being.

6.4.4 Improved quality of life

Base case

As previously stated in section 3.6, the focus of this study in terms of assessing quality of life impacts has been limited to YLD (that is, it does not focus on premature mortality). The disability weight that is applied to estimate the YLD for an individual with Cerebral Palsy varies significantly depending on whether or not the individual is intellectually disabled. The four weightings that are applied to individuals with Cerebral Palsy are as follows (from Table 3):

- 0.17 – without intellectual disability
- 0.29 – mild intellectual disability
- 0.43 – moderate intellectual disability
- 0.82 – severe intellectual disability.

The appropriate disability weighting is then applied to the estimate for the VOLY of $288,965 (June 2011 dollars) to produce an annual per person cost. This cost estimate ranges from $49,124 to $236,951. These estimates represent the annual cost of a reduction in quality of life for an individual with Cerebral Palsy.

Economy-wide cost estimates

Access Economics produced an economy-wide estimate of the cost of the reduction in quality of life arising as a consequence of Cerebral Palsy in Australia in 2007. This includes both morbidity and premature mortality. In 2007, the total DALYs attributed to Cerebral Palsy in Australia was 18,211. Of this total, 14,748 DALYs related to YLD. The estimated cost of this was $2.4 billion in 2007.180

Impact of early intervention

The impact of a disability on quality of life is determined by a range of factors including physical and mental health issues, living independence, mobility, etc. While there is a lack of longitudinal studies assessing the impact of early intervention on

these factors for individuals with Cerebral Palsy, we consider that, based on the evidence that is available, some improvement is plausible.

The benefits from improvements in quality of life as a result of early intervention can be estimated by assessing the potential impact on the disability weighting for individuals with Cerebral Palsy under different scenarios. It is recognised that the scenarios are hypothetical.

**Estimating potential benefits**

As stated above, the disability weighting for individuals with Cerebral Palsy varies significantly subject to the presence of intellectual disability. However, regardless of the individual’s disability weighting, an improvement in quality of life as a result of early intervention will result in the weighting, and associated cost, being reduced. Three reductions were applied to the lowest and highest disability weightings for Cerebral Palsy (0.17 and 0.82) to present the possible range of potential benefits of early intervention in terms of quality of life. The reductions applied were:

- a conservative reduction of 10% (reduces the weighting for individuals without intellectual disability by 0.017 and the weighting for individuals with a severe intellectual disability by 0.082);

- a ‘mid-point’ estimate of 20% (reduces the weighting for individuals without intellectual disability by 0.034 and the weighting for individuals with a severe intellectual disability by 0.164); and

- a significant reduction of 30% (reduces the weighting for individuals without intellectual disability by 0.051 and the weighting for individuals with a severe intellectual disability by 0.246).

There is no evidence available to support the percentage reductions. The intention is to show what the benefit might be if such improvements were realised. These reductions were applied to the VOLY ($288,965) to derive an estimate for the benefit associated with the improvements in quality of life potentially achievable through early intervention. The annual per person benefits estimated were as follows:

- for an individual without intellectual disability:
  - $4,912 under the conservative scenario
  - $9,825 under the median (or mid-point) scenario
  - $14,737 under the significant improvement scenario

- For an individual with a severe intellectual disability:
– $23,695 under the conservative scenario
– $47,390 under the median (or mid-point scenario
– $71,085 under the significant improvement scenario.

The lifetime benefits were estimated over 20 and 40 years of adult life, using discount rates of 3% (base case) and 6%.

<table>
<thead>
<tr>
<th>Improvement scenario</th>
<th>20-year benefit</th>
<th>40-year benefit</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>3% disc. rate</td>
<td>6% disc. rate</td>
</tr>
<tr>
<td></td>
<td>3% disc. rate</td>
<td>6% disc. rate</td>
</tr>
<tr>
<td>Individuals without intellectual disability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conservative</td>
<td>73,084</td>
<td>56,345</td>
</tr>
<tr>
<td>Median</td>
<td>146,168</td>
<td>112,690</td>
</tr>
<tr>
<td>Significant</td>
<td>219,253</td>
<td>169,035</td>
</tr>
<tr>
<td>Individuals with a severe intellectual disability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conservative</td>
<td>352,524</td>
<td>271,782</td>
</tr>
<tr>
<td>Median</td>
<td>705,048</td>
<td>543,563</td>
</tr>
<tr>
<td>Significant</td>
<td>1,057,572</td>
<td>815,345</td>
</tr>
</tbody>
</table>

Based on the scenarios modelled, the conservative scenario of a 10% improvement in quality of life (or a 10% reduction in the disability weighting) for 20 years of adult life produces a present value benefit ranging from $73,084 to $352,524. A more optimistic scenario could yield benefits ranging from $219,253 to $1,057,572 over the same time period. The longer these improvements are maintained throughout adult life, the higher the benefits.

The above estimates show that even small improvements in quality of life can produce significant benefits for some individuals with Cerebral Palsy. Recognising the issues involved in reliably measuring quality of life impacts (as discussed in section 3.6), even small improvements in this metric alone could outweigh the cost of early intervention. The estimates also demonstrate the significance of the presence of intellectual disability in terms of the potential benefits from improvements in quality of life.

6.4.5 Improved health outcomes

The literature review indicated that individuals with Cerebral Palsy can experience a number of functional problems and impairments throughout their life, including cognitive impairments, speech difficulties, and problems with mobility and spasticity. These impairments can lead to health problems including respiratory difficulties, gastrointestinal issues, problems with cardiovascular system functioning, hip pain and dislocation, nutritional deficiencies, etc. Early intervention can target the underlying
problem but can also prevent, or reduce the impact of, these associated health problems.

For example, it is considered plausible that by improving mobility and physical outcomes, early intervention will enable orthopaedic surgeries to be undertaken more efficiently. In effect, this will result in changes to the types of surgery that are required in the future (i.e. hip surveillance leads to early detection which results in less salvage surgery and reduced hip dislocation). The reduced costs associated with the changes in types of surgery required would represent a benefit of early intervention.

### 6.4.6 Improved quality of life for families

There is considerable evidence suggesting that caring for a child or adult with a disability can have a significant impact on the family, including families of children with Cerebral Palsy. While some of the costs associated with this impact are accounted for under the costs of informal care, there are also other costs including the impacts of higher levels of stress in the family environment (e.g. marital breakdown).

As previously stated in section 3.7, there is currently no accepted methodology available for estimating these costs and as a result they have not been included in this study. We consider it reasonable to assume that early intervention has the potential to generate significant and positive benefits for families, as is evidenced by some of the studies contained in Appendix C. Accordingly, while these benefits cannot be directly valued they should not be ignored.

### 6.5 Summary of benefits from early intervention

In summarising the results of this assessment it is firstly necessary to reiterate the absence of robust data on long-term outcomes for individuals with Cerebral Palsy that receive early intervention. However, we consider that it is reasonable, based on the evidence that is available, to conclude that early intervention does have the potential to generate material benefits. In particular, short-term studies have demonstrated that early intervention can improve mobility and reduce spasticity in young children with Cerebral Palsy. It can also improve areas such as communication and nutritional status, and the child’s overall participation in their environment.

The benefits of early intervention are also likely to vary considerably between children with Cerebral Palsy. These benefits are subject to a number of factors, including:

- the nature and extent of the child’s impairments before intervention
- their age of referral to an intervention program
• the nature and intensity of the intervention received
• the child’s response to the intervention
• the influence of other environmental and contextual factors
• the presence and influence of comorbid conditions and/or associated health problems.

It is also important to recognise the heterogeneous nature of the disability. The functioning of individuals with Cerebral Palsy not only varies based on the severity of the disability but also on the specific nature of the individual’s impairments. This is significant as Cerebral Palsy involves a range of impairments, which vary considerably. The specific nature of these impairments will have a significant impact on the benefits of early intervention for a child with Cerebral Palsy.

Accordingly it is not appropriate to provide point estimates of the total benefits or even a potential range of outcomes. The ability to provide such estimates would be improved by robust long-term outcome studies as this would provide evidence in relation to the early intervention strategies that work best for children with Cerebral Palsy under particular conditions. These studies would need to address strategies used for different types of impairments (that is, cognitive functioning, motor functioning etc).

In section 9 we hypothesise a range of potential scenarios for a child with a disability that has received early intervention. This recognises the wide spectrum of outcomes that could be observed between different disabilities and for any group of children with the same disability (noting that this is particularly relevant for Cerebral Palsy). We also recognise that the costs of early intervention can vary according to the nature of the program and the needs of the child and the family.

These scenarios hypothesise different combinations of outcomes, recognising that the outcome achieved in each area must be referenced to the outcomes that the child would otherwise have achieved in the absence of early intervention. Any one of these outcomes is considered plausible for a child with Cerebral Palsy, having regard to the variables listed above. However, we cannot ascribe any probabilities to any of these scenarios being achieved.

Overall, this shows that early intervention for children with Cerebral Palsy has the potential to generate significant positive economic benefits, recognising the variability of outcomes across the spectrum of the disability. Apart from the fact that this does not capture the full spectrum of outcomes that may be achievable, it is also important to
remember that there are also other benefits that have not been quantified, such as improvements in the quality of life for families. Those benefits alone may be material.

It is also important to recognise that a child who receives early intervention may still require additional services and supports (including assistive technology), potentially throughout their adult life. However, to the extent that the child’s long-term outcomes have still been improved as a consequence of early intervention, this has no impact on the realisation of the benefits described above.
7  Hearing impairment

7.1  Overview of the disability

Hearing impairments are often characterised according to the cause of the impairment. Hearing loss in individuals can either be congenital or acquired. Congenital hearing loss refers to impairments acquired at birth or soon after while acquired hearing loss refers to impairments not present at birth (i.e. acquired at a later time).

This study has focused on the characteristics and outcomes for individuals with Permanent Childhood Hearing Impairment (PCHI), as it is this category of individuals that are relevant to the assessment of the impacts of early intervention. PCHI can be caused by genetic factors, ototoxic drugs, damage to the unborn child from a virus such as rubella, serious cases of jaundice, premature birth, a lack of oxygen at birth, other birth traumas, meningitis and other viruses, and serious head injuries.\(^{181}\)

Hearing impairment can have significant negative impacts on child development in the areas of auditory, speech and language skills, educational outcomes, social and communication development, perceptual processing and psychosocial development.\(^{182}\) Hearing impairments can also seriously disrupt the development of personal relationships and lead to personal and social problems, including depression, loneliness, self-esteem issues and diminished functional status.

7.2  Prevalence

There have been several studies that have assessed the prevalence of hearing impairments in society. This study focuses on prevalence estimates relating to individuals that are either born with a hearing impairment or acquire a hearing impairment very early in life. Table 24 presents an overview of past estimates of the prevalence of hearing impairment in young children.

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Table 24 Results from past studies on the prevalence of hearing impairments in young children

<table>
<thead>
<tr>
<th>Source</th>
<th>Prevalence estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australian Hearing (2011)</td>
<td>Estimated that between 9 and 12 children per 10,000 births in Australia have moderate or greater hearing loss in both ears</td>
</tr>
<tr>
<td>Ching (2009)</td>
<td>It is estimated that 1-2 children out of every 1,000 have permanent hearing loss</td>
</tr>
<tr>
<td>Yoshinaga-Itano, et al (1998)</td>
<td>Hearing loss that is bilateral and permanent is estimated to be present in 1.2 to 5.7 per 1,000 live births</td>
</tr>
<tr>
<td>Upfold &amp; Ipsey (1982)</td>
<td>Australian longitudinal study estimated a rate of hearing loss in children of 2.6 per 1,000</td>
</tr>
<tr>
<td>Australian Hearing (2005)</td>
<td>Australian longitudinal study estimated a rate of hearing loss in new births of 1.2 per 1,000 and a rate of hearing loss in children of 2.5 per 1,000</td>
</tr>
<tr>
<td>Yoshinaga-Itano, et al (2000)</td>
<td>A study of new births in the United States estimated the rate of hearing loss in new births and in children at 2.5 per 1,000</td>
</tr>
<tr>
<td>Mehl &amp; Thomson (2002)</td>
<td>A study of new births in the United States estimated a rate of hearing loss in new births of 1.54 per 1,000</td>
</tr>
<tr>
<td>Fortnum, et al (2001)</td>
<td>A longitudinal study in the United Kingdom estimated a rate of hearing loss in new births of 0.91 per 1,000 and a rate of hearing loss in children of 2.1 per 1,000</td>
</tr>
<tr>
<td>Schroeder, et al (2006)</td>
<td>Prevalence of PCHI in the United Kingdom estimated at 112-133 infants per 100,000 births</td>
</tr>
<tr>
<td>Davis &amp; Hind (1999)</td>
<td>Prevalence of PCHI estimated at 1 in 752 children</td>
</tr>
</tbody>
</table>

The average prevalence rate of the estimates reported in the table above is 1.86 per 1,000 births. There were 297,900 births registered in Australia in 2010.183 This means that approximately 554 children are born with a hearing impairment on an annual basis. This prevalence estimate is reduced to 506 (1.70 per 1,000 births) when only those prevalence estimates relating to new births are considered (that is, the case where the child is born with a hearing impairment).

### 7.3 Early intervention strategies

The most common treatment of children with severe or profound hearing loss is the fitting of amplification devices in the form of hearing aids or implants. Early screening programs play a significant role in the early treatment of hearing impairment due to the importance of early detection in terms of the outcomes that are achieved. There have been several studies undertaken on the importance of early detection for the effective treatment of hearing impairment. A summary of these studies is provided in Appendix D.

As with all of the disabilities that have been examined in this review, research into the underlying theory of the development of children with hearing impairments, and how this can be impacted by the fitting of a hearing device such as a Cochlear implant, continues to grow. As noted by Kang et al (2004), the ability to hear sounds “does not

automatically guarantee the acquisition of understanding speech in deaf children who have yet to learn auditory language.”\textsuperscript{184} It is also understood that the plasticity of the brain of a young child that is fitted with an implant is important in relation to regaining auditory sensory function as well as the belated learning of auditory language. Their study highlighted:\textsuperscript{185}

In the normal hearing children, both the auditory and visual sensations were available from the very beginning of the language acquisition. If profound deaf children had developed their own speech perception before surgery based only on uncompromised sensory functions such as vision, the course of the auditory language acquisition of these deaf children following the CI must be very different from that of normal developing children.

Accordingly, children can still have difficulties acquiring language after the fitting of a cochlear implant because the child’s early auditory deprivation has secondary impacts, including disturbances in visual sequence learning abilities, which has shown to be correlated with language outcomes.\textsuperscript{186} The evidence shows that these impacts will not necessarily ‘self-correct’ following the fitting of an implant.

A paper by Champoux et al (2008) examines the issue that visual stimuli that are initiated to facilitate auditory processing in children that are hearing impaired can continue to persist after the child has been fitted with an implant.\textsuperscript{187} This in turn can be detrimental to the child’s subsequent auditory performance. Early intervention, or in this case, ‘retraining’ the brain to process and respond to stimuli, could therefore be of fundamental importance in preventing these adverse impacts. Based on what we know about plasticity, this needs to occur as early as possible.

In terms of early intervention treatments, most of the recent literature examines Auditory-Verbal Therapy (AVT), which is now one of the more commonly applied forms of intervention. This form of intervention involves individualised, diagnostic sessions that include the use of hearing technology with the aim of acquiring listening as a primary modality to facilitate the development of spoken language. The method is based on the notion that most children with mild to profound hearing loss can learn to

communicate through spoken language if provided with appropriate amplification in addition to listening and language stimulation.\textsuperscript{188}

The Box below provides a summary of the Listen & Talk Programme – a significant AVT intervention program that is provided in the Singapore General Hospital.

**Box 3 The Listen & Talk Programme at the Singapore General Hospital**

The Listen & Talk Programme was established in July 2001 in the Department of Otorhinolaryngology of the Singapore General Hospital. The therapy provided under the program combines the three disciplines of audiology, speech-language pathology and the teaching of the deaf. The program uses the standardised curriculum of the Auditory-Verbal International as a guide.

Children included in the programme are fitted with an appropriate amplification device upon diagnosis of their hearing impairment. A major component of the programme is the training and support that is provided to parents. Parents and caregivers are trained in how to develop their child’s listening and language skills through participation in weekly individualised parent guidance sessions. Parents also receive weekly targets in relation to audition, speech, language, cognition and communication. Therapists and parents jointly conduct sessions in the comfort of the family’s home, with an increased focus placed on family activities and interests. Parent Groups are also held once every six weeks to provide additional education and support.

The multidisciplinary team responsible for administering the Listen & Talk Programme comprises medical professionals, audiologists, auditory-verbal therapists, a medical social worker and a psychologist. There is also the potential for therapists to collaborate with physiotherapists, occupational therapists, speech therapists and school educators when required.


It is important to emphasise that this is not the only form of intervention available. It was the most common form of intervention for which there is evidence in the literature and accordingly it can be considered a ‘case study’ for the outcomes that could be achieved for children that are born with a hearing impairment. The fact that we have not focussed on alternative models of early intervention does not mean that they do not have the potential to generate positive outcomes for children with hearing impairment and their families, although the nature and extent of the benefits (and costs) may be different.

### 7.4 Costs of early intervention

Based on consultation with a major service provider, a reasonable estimate for the provision of early intervention services under the AVT approach is approximately $55,000 per child.\textsuperscript{189} These costs are based on program duration of five to six years.


\textsuperscript{189} We haven’t discounted these costs over those six years. This is a conservative assumption (and recognises that there may be other costs that we have not captured).
with annual costs varying with the intensity of intervention over the program’s duration. These costs cover therapy provided to children, parent education and the cost of resources used in play groups and other activities associated with the program. The costs associated with hearing amplification devices are not included in this estimate.

We have not discounted these costs over the period. This is a conservative assumption (and recognises that there may be other costs that we have not captured).

We recognise that different programs involve different costs. This estimate should therefore be considered indicative only.

### 7.5 Benefits of early intervention

There is a considerable amount of literature available on the benefits of early intervention for children with hearing impairment and in particular AVT. This literature is summarised in Appendix D. There has been an increased focus on this research over the past few years, with several studies having been conducted assessing the short to medium term outcomes that have been achieved by children with hearing impairment that have received early intervention.

The following sections examine the potential economic benefits that can be achieved as a result of early intervention. In assessing the benefits of early intervention we consider that it is important to do so independent of the fitting of the hearing device. In other words, we are assuming that the key question we need to address is not whether the fitting of a hearing device will improve outcomes for a child with a hearing impairment, but whether in conjunction with that, early intervention alters outcomes for the child relative to the outcomes they may have achieved in the absence of intervention (recognising that early intervention can also benefit families as well).

#### 7.5.1 Education

**Base case**

A review of the relevant literature on outcomes for individuals with hearing impairment shows that children with a hearing impairment develop reading, language and communication skills at a slower rate compared to their non-impaired peers. While the literature does not contain evidence of the special education needs of children with hearing impairment, it is considered reasonable to assume that children with a hearing impairment may require additional special education resources relative to their non-impaired peers. In most cases, these services are likely to be provided in a mainstream school environment through a teacher aide.
Economy-wide estimates

Access Economics’ 2006 study on the social and economic costs of hearing impairment in Australia estimated the additional education costs attributable to hearing impairment in 2005. This study used international data to form the basis of its cost estimates, with the Centre for Special Education Finance in the United States estimating the average spending ratio for deaf and hearing impaired students compared to the non-impaired student population at 2.4:1. Applying ABS population estimates and data from the Australian Ministerial Council on Education, Employment, Training and Youth Affairs (MCEETYA) resulted in a total cost estimate for the additional education services provided to children with a hearing impairment of $117.2 million per annum.

Impact of early intervention

It has been reported that with early detection, amplification and effective individualised early intervention, up to 80% of children born deaf can succeed in mainstream education. The following studies have assessed the educational achievements and levels of development of children with a hearing impairment that have received early intervention:

- Durieux-Smith et al (1998) reported that children who had received early intervention had been able to function effectively and achieved scores within the average range on measures of communication, self-perception and academic skills;

- Moeller (2000) found that regardless of the degree of hearing loss, children enrolled early in early intervention achieved language scores that approximated those recorded by their non-impaired peers;

- Diller, Graser and Schmalbrock (2001) found that all children (in a group that had received early intervention) with correctly adjusted hearing devices exhibited rates of hearing development consistent with children with normal hearing.

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Dornan et al (2010) found that 79% of a group of children that had received early intervention scored within the typical range with respect to language skills with the early intervention group achieving mean total language scores that were only 2.1 months less than the mean chronological age.\textsuperscript{195}

On the basis of the outcomes reported in the literature, it is concluded that early intervention improves education outcomes for children with a hearing impairment, and therefore would be expected to reduce the cost associated with providing special education services.

\textit{Estimating the potential benefits}

As is stated in section 3.2, the additional per person cost of providing special education services to students with disabilities is estimated at $15,367 per annum. Given that the most likely outcome for a child with a hearing impairment is education in a mainstream school with additional support (rather than a special school environment), applying this estimate as the base case cost without intervention could still overstate the average costs incurred. We therefore consider it appropriate that a lower ‘base case’ cost estimate be adopted. For the purpose of this study we have therefore assumed that the starting point (for a child that has not received early intervention) is an annual cost of $7,684, which is 50% of the average additional cost of special education for children with disabilities,\textsuperscript{196}

In the event that early intervention results in a child that would have required special education services no longer requiring these services, this cost is avoided and therefore represents a benefit from early intervention. Over 12 years of schooling, the total benefit (in Present Value terms) is estimated at $76,500 using a discount rate of 3\% (base case) and $64,400 using a discount rate of 6\%.

The estimate of $76,500 is considered to be the upper bound estimate for the benefits of early intervention in relation to the reduction in special education costs. Variations between individuals in terms of the intensity of special education services required in the absence of early intervention, and also the extent to which early intervention will reduce the need for these services to be provided, will mean that the actual total benefits are likely to lie between $0 and $76,500.


\textsuperscript{196} We have no data to estimate the cost savings that may be realised and in practice, this will vary for each child. In the absence of this data, it is considered appropriate to take the mid-point (i.e. 50\% of the total cost estimate), recognising that the actual cost savings for a child could be higher or lower than this.
7.5.2  Improved employment outcomes

Base case

The ability to secure competitive employment is a key economic benefit associated with early intervention across the disabilities, including hearing impairment. This carries a significant economic benefit to society as the individual is contributing to overall production and no longer requires welfare payments.

In assessing the magnitude of this benefit it is firstly useful to establish the baseline outcome for individuals with a hearing impairment that do not receive early intervention. The 2006 Access Economics report contains a comprehensive summary of the results of previous studies conducted on the employment status of hearing impaired individuals. Table 25 provides a summary of the studies included in this report.

### Table 25  Summary of studies assessing employment outcomes for people with a hearing impairment

<table>
<thead>
<tr>
<th>Source</th>
<th>Study details</th>
<th>Employment outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mowry (1988)</td>
<td>Study comparing the earnings of hearing impaired and non-hearing impaired workers</td>
<td>• Study found that people who are deaf earned on average 19% less and people who are hard of hearing earned 8.5% less than non-impaired individuals employed in the same category, even after rehabilitation</td>
</tr>
<tr>
<td>O’Neill (1999)</td>
<td>Study based on an analysis of the 1994 US National Health Interview Survey data relating to workers with hearing impairment</td>
<td>• Participation rates for people with hearing loss was 67% compared to 75% for the non-hearing impaired</td>
</tr>
<tr>
<td>Mohr, et al (2000)</td>
<td>Study evaluating the societal costs of severe to profound hearing impairment in the US</td>
<td>• Estimated the cost of severe or profound hearing loss in the US at $297,000 over the lifetime of the individual, with the majority of costs attributable to reduced work productivity</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Reduced productivity accounted for 67% of societal lifetime costs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• People with severe to profound hearing loss earn 50-70% of their non-impaired peers, corresponding to a loss of $220,000-$440,000 over a lifetime</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Following labour force participation rates reported:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>– 59% for 18-44 yrs (compared to 77%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>– 49% for 45-64 yrs (compared to 68%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>– 7% for 65+ yrs (compared to 13%),</td>
</tr>
<tr>
<td>Ruben (2001)</td>
<td>Study considered the costs to the US economy of different types of communication disorder</td>
<td>• Estimated that income of people with hearing impairment was 40-45% that of the non-impaired population</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Found that the employment rate for people with difficulty hearing was 64.4% compared to 74.8% for the non-impaired population</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Employment rate for people who are unable to hear was estimated at 50.4%</td>
</tr>
<tr>
<td>RNID (Royal National Institute for Deaf People)</td>
<td>Survey of 1,099 people who were profoundly deaf aged</td>
<td>• Unemployment rate across all respondents was 19% compared to 5% for the non-impaired population</td>
</tr>
</tbody>
</table>

Several of the studies also reported a reduction in average earnings for people with hearing impairments relative to the non-impaired population, with, on average, workers with a hearing impairment earning 28% less than their non-impaired peers. This in turn may be symptomatic of underemployment, that is, the person is able to get a job but it does not reflect their full potential.

The key issue with this data is that we do not know what the statistics are likely to be for an individual that receives a hearing device but no early intervention. As a population, it is evident that individuals with a permanent hearing impairment obtain employment at lower rates than the non-impaired population in addition to earning significantly less than their non-impaired peers. However, we remain unclear as to the most likely employment outcomes for individuals with hearing devices that have not received early intervention.

*Economy-wide estimates*

The study by Access Economics included an assessment of the loss of productivity resulting from employment impacts attributable to hearing loss. The study estimated the annual cost at $6.67 billion. This estimate was based on the assumption that the difference in the proportion of individuals with and without a hearing impairment in paid work was 6.8%.  

*Impact of early intervention*

While there are no longitudinal studies that have specifically assessed the impact of early intervention on the employment outcomes for individuals with a hearing impairment, there are several studies that have assessed school-aged outcomes for individuals that have received early intervention. Given the nature of the disability, it is considered that levels of educational attainment provide a strong indication of the likely employment outcomes for individuals with a hearing impairment.  

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199 The impact of hearing impairment on an individual’s functioning is typically limited to hearing and speech-related capabilities (noting that this can be extended to include social interactions which may also impact on adult outcomes). In this manner hearing impairment differs from the likes of autism, Down Syndrome and Cerebral Palsy in that its impacts are relatively contained. If it can be established that an individual with a hearing impairment can perform as well as non-impaired peers in an educational environment, it is therefore considered that there is a high likelihood that this will be reflected in future outcomes in terms of employment.
As demonstrated by the studies discussed in section 7.5.1, there is strong evidence indicating that early intervention significantly improves the levels of educational attainment achieved by individuals with a hearing impairment. It would be expected that these improvements would translate to individuals with a hearing impairment obtaining competitive employment at rates more comparable to their non-impaired peers (noting that other factors can impact on employment outcomes and that actual outcomes will vary across individuals depending on the severity of impairment).

While the available evidence provides a strong basis for concluding that early intervention improves employment outcomes for individuals with a hearing impairment, it is still necessary to recognise the absence of any long-term studies that have fully tested this hypothesis. The evidence base would benefit from longer term studies confirming that the short to medium term benefits achieved by early intervention are maintained in adult life and subsequently translate into improved employment outcomes. In saying this, we would expect that if an individual with a hearing impairment is able to maximise their educational achievements as a consequence of early intervention, there is no reason why these benefits should not be able to be sustained in the long-term, in the absence of any other intervening factors.

*Estimating the potential benefits*

Based on the outcomes studies that have been assessed, employment rates for individuals with a hearing impairment are slightly less than the equivalent rates for non-impaired peers, with the earnings of individuals with a hearing impairment being significantly lower. The majority of individuals with hearing impairment are able to secure competitive employment however there could be significant underemployment.

On this basis, the benefits of early intervention are to be assessed in relation to the potential for the average earnings of individuals with a hearing impairment to increase to a level that is comparable with average earnings of their non-impaired peers. This in turn provides a wider benefit to the community as that individual’s contribution can increase productivity in the economy.

As discussed in section 3.3, there are a number of important qualifications to this approach. In particular, it assumes that the employment of the person results in a net increase in productivity in the economy, and that this increase in productivity equates to their salary.

Section 3.3 contains the estimates and parameters used to estimate the productivity benefits associated with improved employment outcomes from early intervention. The values to be applied in this section are as follows:
• based on ABS average weekly earnings data, average annual earnings for all employees of $53,040 ($65,052 for males and $41,600 for females);

• a lifetime estimate for average total earnings across all employees (in Present Value terms) of $1.14 million ($1.398 million for males and $0.894 million for females); and

• based on the minimum wage, average annual earnings of $30,644 per annum or lifetime earnings of $0.658 million.

In the event that early intervention enables an individual that would have otherwise earned the minimum wage to earn a wage that is consistent with the average wage, the equivalent benefit would be an increase in annual earnings of $22,396, or $481,300 in Present Value terms over a 35 year working life (using a 3% discount rate).

Where early intervention enables an individual that would otherwise only be able to be employed in a part-time position at the average wage to obtain full-time employment (assuming that person wants full-time employment), the equivalent benefit would be an increase in annual earnings of $19,890, or $427,400 in Present Value terms over a 35 year working life.

Table 26 presents the annual and lifetime benefits relating to gains in productivity as discussed above. The lifetime benefits are presented using discount rates of 3% (base case) and 6%.

<table>
<thead>
<tr>
<th>Benefit</th>
<th>Annual benefit ($/yr)</th>
<th>Lifetime benefit – 3% discount rate</th>
<th>Lifetime benefit – 6% discount rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improvement in earnings from minimum wage to average wage</td>
<td>22,396</td>
<td>481,300</td>
<td>324,700</td>
</tr>
<tr>
<td>Upgrade from part time to full time position at average wage</td>
<td>19,890</td>
<td>427,400</td>
<td>288,400</td>
</tr>
</tbody>
</table>

Note: Part-time estimates are generated based on 25 hours per week (i.e. 62.5% of full-time rate). For presentation purposes the estimates have been rounded.

These estimates show that improving the intensity of employment or rate of earnings (as a direct result of early intervention) by an individual with hearing impairment carries significant benefits (lifetime benefits of $427,400 and $481,300 respectively). It is considered appropriate to use these two scenarios to estimate the potential benefits from early intervention as the literature indicates that while the majority of individuals with a hearing impairment do obtain competitive employment, it is often at wage levels significantly below their non-impaired peers. There are also potential benefits where early intervention enables individuals with a hearing impairment to obtain full-time employment at a rate that is above the average wage.
This could also be seen to proxy the benefit of reducing underemployment. In other words, rather than not being able to gain competitive employment at all, the key risk for a person with a hearing impairment may be that they are not able to secure a job that reflects their full potential.

The way in which these benefits can accrue will vary between individuals and will also depend on the most likely outcomes that would have been achieved for each individual in the absence of early intervention. Overall, the benefit lies in the ability of the person with a hearing impairment to maximise their potential, recognising that there are a number of other factors impacting employment, some of which are external.

7.5.3  Improved living independence

Based on a review of the literature, it is considered that the proportion of individuals with a hearing impairment that require assistance with daily living tasks, particularly into adulthood, is extremely low. On this basis, we have not assessed this as a potential benefit of early intervention for people with a hearing impairment.

7.5.4  Improved quality of life

Base case

As previously stated in section 3.6, the focus of this study in terms of assessing quality of life impacts has been limited to YLD (that is, we have not considered mortality). As outlined in Table 3, the AIHW disability weighting for individuals with severe hearing impairment is 0.37 and 0.12 for moderate hearing impairment.

As discussed previously, we are not seeking to evaluate the impacts of children receiving hearing devices. What we are seeking to evaluate is the potential benefits of early intervention that is provided to a child once they have received a hearing device. Accordingly, the disability weighting for severe hearing loss is not appropriate as a ‘base case’ assumption. In its 2006 study of the economic impact of hearing loss in Australia, Access Economics assumed that a hearing aid reduced the disability weighting for an individual with a severe hearing impairment to the disability weighting for an individual with a moderate impairment, which is 0.12. We have therefore assumed that this is the base case assumption for the disability weighting.

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200 It is also important to recognise that the ‘base case’ for this assessment is an individual with a hearing impairment that has been supplied with a correctly adjusted hearing device.

This disability weighting is then applied to the estimate for the VOLY of $288,965 (June 2011 dollars) to produce an annual per person cost of $34,676. This represents the base case for the reduction in quality of life on an annual basis for a person with severe hearing loss with a correctly fitted amplification device.

**Economy-wide estimates**

Access Economics’ study included an estimate for the ‘burden of disease’ associated with hearing impairment in Australia in 2005. This estimate was produced based on disability weightings calculated by the AIHW based on hearing loss in the better ear. The weightings used by Access Economics are as follows:

- 0.018 to 0.020 for mild hearing loss
- 0.104 to 0.120 for moderate hearing loss
- 0.324 to 0.370 for severe hearing loss.

In order to take into account the impact of hearing aids on quality of life, the weighting applied to individuals with a hearing aid were downgraded by one level of severity (i.e. an individual with severe hearing loss but with a hearing aid was attributed a disability weighting of 0.104 to 0.120 as opposed to 0.324 to 0.370).

Applying population data to the disability weightings resulted in a gross estimate for the burden of disease attributable to hearing impairment of $15.4 billion (reduced to $11.3 billion when converted to a net estimate).

**Impact of early intervention**

The impact of a disability on quality of life is determined by a range of factors including physical and mental health issues, living independence, mobility, etc. In relation to hearing impairment, the main impacts relate to hearing and language abilities and social and communication skills.

While there are no longitudinal studies that have assessed the long-term impacts of early intervention for individuals with a hearing impairment on quality of life, there is considerable evidence available from short to medium term studies that suggest that early intervention results in improvements in hearing and language abilities and other areas of functioning. It is also not evident from the literature that the longevity or persistence of any improvements achieved is an area of considerable uncertainty here.

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202 These weightings are not adjusted for the impact of amplification devices.

203 This estimate was converted to a net estimate by removing production losses net of tax and health costs borne out-of-pocket and adding welfare receipts.
At the same time, this does not mean that long-term outcomes studies should not be pursued.

These studies indicate that by enabling a child with hearing impairment to maximise their potential, early intervention is likely to improve quality of life in the long-term and therefore achieve some benefits. These benefits can be estimated by applying reductions to the disability weighting (which as outlined in section 3.6.1, represents the portion of a year of healthy life lost due to disability), which is then applied to the VOLEY in order to value the improvement in quality of life per annum.

**Estimating the potential benefits**

As has been previously discussed, a disability weighting of 0.12 has been adopted for estimating the impact of early intervention on quality of life in this study. In the absence of any robust data linking early intervention to long-term improvements in the quality of life for individuals with hearing impairment, we can only hypothesise the benefits based on possible scenarios. Three reductions were applied to the disability weighting of 0.12 to assess the potential benefits of early intervention in terms of quality of life – a conservative reduction of 10% (reduces the disability weight by 0.012), a significant reduction of 30% (reduces disability weight by 0.036) and a mid-point estimate of 20% (reduces disability weight by 0.024). There is no evidence available to support the percentage reductions. The intention is to show what the benefit might be if such improvements were realised.

These reductions were applied to the VOLEY ($288,965) to derive an estimate of the annual benefit. The annual per person benefits estimated were as follows:

- $3,468 under the conservative scenario
- $6,935 under the median (or mid-point) scenario
- $10,403 under the significant improvement scenario.

A present value of the lifetime outcomes is also estimated over 20, 40 and 60 years of adult life, as shown in Table 27. Estimates are presented using a discount rate of 3% (base case) and 6%.

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204 The benefits of early intervention for hearing impaired individuals are discussed in detail in Appendix D.
Based on the scenarios modelled above, the conservative scenario of a 10% reduction in the disability weighting (reduction of 0.012) for 20 years of adult life produces a present value benefit of $51,600. A more optimistic scenario could yield benefits of $154,800 over the same time period. The longer these improvements are maintained throughout adult life, the higher the benefits.

This shows that if even small improvements are achieved (and sustained for some period), the benefits are significant. Recognising the issues involved in reliably measuring quality of life impacts, improvements in this metric alone could well outweigh the cost of early intervention.

7.5.5 Improved health outcomes

Base case

Access Economics used 2000-01 AIHW data to determine an estimate for direct health system costs associated with hearing impairment. The most significant areas of expenditure reported were health professionals and hospital out-patient costs. Hearing aids and implants were not included in their estimates. The 2005 per person cost estimated by Access Economics was $69.72 per person with hearing loss, over 70% of which was accounted for by ‘other health professionals’ and ‘hospital out-patient costs’.

Economy-wide cost estimates

Access Economics applied ABS population estimates and prevalence data to estimate the total direct health costs attributable to hearing impairment in 2005. This resulted in a total cost estimate of $247.5 million. The total cost of hearing aids and implants was estimated at $367.7 million, however this was not included in the estimate for direct health system costs.

Impact of early intervention

None of the studies conducted to date have assessed the impact of early intervention services on health outcomes. Despite the plausibility of improvements in outcomes, we
do not consider that we have a sufficient evidence base to draw a direct linkage between early intervention and health care outcomes. Accordingly, we have not sought to ascribe any benefits here. Also, it is important to note that on a per person basis the estimates for direct health expenditure for individuals with hearing impairment are relatively low, meaning that the benefits are unlikely to be very significant.

7.5.6 Improved quality of life for families

The review of the literature on hearing impairment did not assess the impact on the quality of life of families. However, it is considered reasonable to assume that early intervention has the potential to generate positive benefits for families by improving outcomes and subsequently quality of life.

These benefits can arise in a number of ways, including helping parents better understand the nature and consequences of their child’s disability, teaching them new skills to facilitate their child’s development (which increase parental confidence as well as assisting the child), reducing stress on parents and other family members, providing them with access to services and connecting them with other parents who have children with hearing impairments.

As previously stated in section 3.7, there is currently no accepted methodology available for estimating the quality of life impact on families and as a result they have not been included in this study. However, while these benefits cannot be directly valued they should not be ignored.

7.6 Summary of benefits from early intervention

While it is necessary to note the absence of robust data with regards to the long-term outcomes for individuals with hearing impairment that receive early intervention, it is also important to note that the nature of the disability means that in the absence of comorbid conditions, short to medium term outcomes can provide a solid evidence base for predicting longer term outcomes (i.e. the impact of hearing impairment is restricted to hearing, speech and language development and related capabilities and does not have any adverse behavioural impacts). It is therefore considered reasonable to conclude that early intervention does have the potential to generate benefits that are well in excess of the costs of early intervention.

Given that the benefits of early intervention are likely to vary considerably between different individuals with hearing impairment (although the variations are not necessarily as significant as some of the other disabilities we have examined), it is not appropriate to provide point estimates of the total benefits or even a potential range. The ability to provide such estimates would be improved by robust long-term outcome
studies that enable more specific connections to be made between early intervention and long-term outcomes in specific areas.

In section 9 we hypothesise a range of potential scenarios for a child with a disability that has received early intervention. This recognises the wide spectrum of outcomes that could be observed between different disabilities and for any group of children with the same disability. We also recognise that the costs of early intervention can vary according to the nature of the program and the needs of the child and the family.

These scenarios hypothesise different combinations of outcomes, recognising that the outcome achieved in each area must be referenced to the outcomes that the child would otherwise have achieved in the absence of early intervention. Any of these outcomes is considered plausible for a child with a hearing impairment, having regard to the variables listed above. However, we cannot ascribe any probabilities to any of these scenarios being achieved.

When interpreting these scenarios, it is also important to remain cognisant of the higher starting point for a child who has received a hearing device or implant (but no intervention) compared to the other disabilities. For example, they are more likely to be able to attend a mainstream school (but require support), and they are more likely to be able to get a job, although could be underemployed.

Overall, this shows that early intervention for children with hearing impairment has the potential to generate significant positive economic benefits. Apart from the fact that this does not capture the full spectrum of outcomes that may be achievable, it is also important to remember that there are also other benefits that have not been quantified, such as improvements in the quality of life for families. Those benefits alone may be material.

As mentioned upfront, based on the information available we have focussed on early intervention for children that have been fitted with an amplification device (hearing aids or cochlear implant). Most of the evidence that was available is for AVT. The underlying theory and analysis suggests that early intervention therapy is an important (if not a necessary) complementary investment to a hearing device. In the absence of this, the child may not have the opportunity to maximise their full potential. While there is considerable uncertainty underpinning the long-term outcomes for some of the other disabilities, of any of the disabilities studied, it would appear that the outcomes for hearing impairment, and specifically the potential for short to medium term outcomes to translate into improved outcomes in adulthood, are most certain due to the nature of the disability (i.e. impairments are constrained to hearing and speech development and associated functions with children not experiencing behavioural impairments).
We have not examined other types of intervention strategies for children with hearing impairments. We must emphasise that the fact that we have not focussed on other intervention strategies that are provided to children with hearing impairments, including those that do not involve the fitting of a hearing device, does not mean that these other strategies may not also be beneficial. However, we cannot draw any specific inferences from the above data in relation to these other strategies, as the benefits and costs may be different.
8 Visual impairment

8.1 Key characteristics

Visual impairment is broadly defined as a limitation in one or more functions of the eye or visual system, most commonly impairment of Visual Acuity (VA), visual fields, contrast sensitivity and colour vision. A person could develop a visual impairment at any stage in life. As the purpose of this study is to examine the potential benefits from early intervention, our particular focus is on visual impairment sustained at birth or during infancy.

Normal vision is recorded as a VA score of 20/20. Visual impairment is normally measured in accordance with this metric, with the first number relating to the furthermost distance (in feet) at which a person can clearly see an object with the second being the distance at which a person with normal vision could see the same object.

The level of visual impairment can vary from eye to eye. It is normal practice for the severity of visual impairment to be gauged based on the level of impairment in the better-seeing eye. Access Economics’ recent study on the economic impact of visual impairment in Australia (which is not limited to childhood blindness) used three different levels of severity of visual impairment, which are defined in Table 28.

Table 28 Severities of visual impairment used in the Access Economics study

<table>
<thead>
<tr>
<th>Severity of visual impairment</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blindness</td>
<td>Best corrected VA of less than 6/60 in the better-seeing eye</td>
</tr>
<tr>
<td>Moderate visual impairment</td>
<td>Best corrected VA of less than 6/18 but better than or equal to 6/60 in the better-seeing eye</td>
</tr>
<tr>
<td>Mild visual impairment</td>
<td>Best corrected VA of less than 6/12 but better than or equal to 6/18 in the better-seeing eye</td>
</tr>
</tbody>
</table>

Notes: ‘Best corrected’ visual impairment means the VA with the best glasses or contact lens prescription for that person, as opposed to ‘presenting’ visual impairment which refers to VA that is unaided. These classifications differ from those used by the World Health Organization, which defines ‘low vision’ as best corrected VA of less than 6/18 and blindness as best corrected VA of less than 3/60.


There are a wide range of conditions that can lead to visual impairment, of which childhood blindness is one. These conditions include: cataract, glaucoma, age-related macular degeneration, corneal opacities, diabetic retinopathy, trachoma and

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206 This term means that a person can see at 20 feet what a person with normal vision can see at 20 feet.
onchocerciasis. Because of these multiple causes, childhood blindness can be a difficult condition to describe. Further, a large proportion of the congenitally blind have multiple impairments that are more or less severe.

In general, childhood blindness refers to a group of diseases and conditions that occur in childhood or early adolescence and result in severe visual impairment or blindness. Causes of childhood blindness vary between regions. In high income countries such as Australia, the most common cause can be lesions of the optic nerve and higher visual pathways. They can also be caused by genetic diseases. A small proportion of cases relate to treatable causes such as cataract and glaucoma while an even smaller proportion relate to Retinopathy of Prematurity.

In contrast, in developing countries the causes are often entirely preventable or treatable and can include: corneal scarring due to Vitamin A deficiency and measles infection; cataract; glaucoma; optic atrophy and ophthalmianenoatorum (a severe eye infection in new-born infants).

8.2 Prevalence

The prevalence of childhood blindness is far greater in developing countries in Africa and Asia than more developed countries. This is due to the higher incidence of malnutrition and the lack of adequate primary health care. The Fred Hollows Foundation has estimated that approximately 75% of the world’s blind children live in developing countries in Africa and Asia. The prevalence of childhood blindness in developed countries is relatively rare.

Access Economics used prevalence estimates for different WHO regions in its report. Australia is located in the WRP-A WHO sub-region. Table 29 includes the prevalence estimates for different age groups for this sub-region used in the Access Economics study.

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207 Access Economics (2010).
### Table 29  Prevalence rates for WPR-A WHO sub-region by age group

<table>
<thead>
<tr>
<th>Severity of visual impairment</th>
<th>Prevalence for &lt;15 years</th>
<th>Prevalence for 15-49 years</th>
<th>Prevalence for 50+ years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blindness</td>
<td>0.12%</td>
<td>0.28%</td>
<td>1.89%</td>
</tr>
<tr>
<td>Moderate-low vision</td>
<td>0.23%</td>
<td>0.42%</td>
<td>3.1%</td>
</tr>
<tr>
<td>Mild-low vision</td>
<td>0.31%</td>
<td>0.57%</td>
<td>4.19%</td>
</tr>
</tbody>
</table>


Only 1.9% of cases of visual impairment were found to be attributable to childhood blindness in the WPR-A sub-region (this estimate decreased to 1.2% when Uncorrected Refractive Error (URE) was taken into consideration).

This low prevalence estimate for childhood blindness is consistent with the estimates reported in other studies. Rahi et al reported the global prevalence of blindness among children had been estimated at around 0.7 per 1,000, while the Fred Hollows Foundation has reported that childhood blindness is the cause of serious visual impairment in 3.9% of cases. However, as outlined above, the condition mostly occurs in poor and developing nations due to malnutrition and a lack of adequate primary health care.

The prevalence of childhood blindness in developed countries such as Australia is therefore significantly lower than the global estimate. Fan et al reported that the prevalence of childhood blindness in children in developed countries has been estimated at 0.2 to 0.3 per 1,000 children, compared to 1.0 to 1.5 per 1,000 children in developing areas.

### 8.3 Early intervention strategies

Childhood blindness is a condition that, if not treated in the early stages of life, is unlikely to be treatable later in life. For example, a child who is seven years of age and has been blind since early childhood often will be unable to respond to surgery as the ability of the brain to recognise visual stimuli has never been exercised.

As noted above, in developed countries, the vast majority of cases of childhood blindness are the result of unavoidable causes. This section focuses on the causes of

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impairments to a child’s vision that are not curable by medical procedures (i.e. visual impairment that exists despite the best possible correction procedures being undertaken).

There is widespread consensus that visual impairment presents a series of developmental risks for a child. Apart from object and space perception, these key risk areas include motor development, cognitive development, socioemotional and language development. It is known that vision affects many aspects of early development, including bonding, wakefulness, balance, gross and fine motor functions, spatial concepts and language and learning. Sight represents an ‘incentive’ for all voluntary skills.

Dale and Salt observe that people with congenital blindness often function extremely well as other senses compensate. However, significant delays in motor, cognitive language and social domains are often observed in the early years, with the most significant delays in those that are more profoundly affected (noting that considerable variation in outcomes can be observed).

They explain how vision can function as a coordinating sense. Without it, other sensory inputs can remain fragmented and disassociated. Early social behaviour and communication also depend on vision. The most serious consequences are for those children showing a developmental setback or regressive disorder in their second to third year.

More is now known about the warning signs of this developmental vulnerability. The identification of these risk factors also shows that there is a window of opportunity in the early years of life before the setbacks have a more significant impact on development. It is therefore critical to promote functional vision as early as possible, as this could yield “the greatest protection towards general development”.

The provision of early intervention services to young children and infants with visual impairment normally involves a multidisciplinary team delivering a home-based program that includes involvement from parents and other family members. The team can include neurodevelopmental paediatric specialists, psychologists, occupational

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therapists, and speech and language therapists.\footnote{221} It may also include a vision specialist and a mobility specialist.\footnote{222}

Simmons identifies the core process for early intervention for children with visual impairment as mediation, or trying to create, improve or facilitate a connection between the child and their environment.\footnote{223} She observes: \footnote{224}

Blind children use their four senses, and sighted children their five, to construct their reality.

Hatton et al observe that an early intervention program targeting infants and young children with visual impairment should be focused on improving the functional outcomes of children, predominantly in the following areas:

- engagement – the amount of time a child spends interacting with the environment in a developmentally or contextually appropriate manner;
- independence – functioning with as little assistance as possible from others; and
- social relationships – ability to communicate, get along with peers, develop trust, interact appropriately, play appropriately and form friendships.\footnote{225}

Elisa et al identified the importance of the ability to ‘reach on sound’ (or the ability of a child with visual impairment to grasp an object that has been presented exclusively through the medium of sound).\footnote{226} This was identified as a condition of, and catalyst for, subsequent developments and can facilitate self-initiated mobility. Early intervention was identified as being of fundamental importance to help a child with visual impairment to develop the ability to reach on sound.

Dale and Salt describe a Developmental Journal which provides a sequential guide to expected development steps for children in the first three years of life.\footnote{227} This focuses on key developmental vulnerabilities, which are:\footnote{228}

\footnotesize{\begin{itemize}
\item Dale, N. & Salt, A. (2007).
\item Dale, N. & Salt, A. (2007).
\end{itemize}}
...integrating the senses in the first year of life, becoming social and communicative, becoming aware of their movement potential, and developing joint attention and co-referencing, and developing shared meaning in language.

Erickson et al examine emergent literacy in children with visual impairment. Emergent literacy is the developmental process beginning at birth where reading and writing skills are established. The recommended intervention practices are home-based and family-centred, with a focus on helping children with visual impairment to develop senses and hand skills to aid development and help them to explore the world around them. A case study observation of two practitioners at work with children with visual impairment in the US showed that early intervention strategies targeted at emergent literacy can be highly effective.

8.4 Costs of early intervention

We have not been able to source any robust estimates of the costs of delivering early intervention for children with visual impairment.

8.5 Benefits of early intervention

There is considerable evidence available indicating that visual impairment can seriously disrupt the development of infants and young children. Infants and young children with visual impairment often demonstrate socio-communicative and development patterns that are significantly different from those of their sighted peers very early in life. Early intervention is therefore considered to be an important part of the treatment of children with visual impairment.

The importance and benefits of early intervention for children with visual impairment is well accepted. Deitz (1993) stated that:

> Early detection of visual impairment, however, and the resulting placement of the appropriate specialists on a child’s multidisciplinary team facilitate the child’s growth and development across all domains and provide support to the team and the family.

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231 Deitz, S.J. (1993). Early services for young children with visual impairment: from diagnosis to comprehensive services. Infants and Young Children, 6(1), pp 68-76.
The benefits of early intervention for children with visual impairment have also been noted elsewhere in the literature, with the following benefits being reported:\textsuperscript{232}

- specific delays in areas such as motor and language development have been found to respond dramatically to early intervention;
- early intervention programs have been found to assist in avoiding the risk of children with visual impairment developing misconceptions regarding the workings of everyday items;
- ensuring a strong foundation for motor and concept development through early intervention assists in maximising overall functioning levels throughout the life of the child; and
- early intervention has been found to have the potential to make a difference in helping children with visual impairment perform closer to the developmental expectations of sighted children.

There are a number of efficacy studies that establish the potential for early intervention to improve developmental outcomes for children with visual impairment. Unfortunately, robust studies that have evaluated the effectiveness of early intervention for children with visual impairment are limited and we have not been able to locate any studies that evaluate long-term outcomes.

Behl, White and Escobar noted that several previous studies had identified substantial benefits for children with visual impairment associated with early intervention programs.\textsuperscript{233} However, they also identified significant methodological issues associated with these studies, most importantly that they lacked comparison groups and properly informed diagnostic professionals.

A more detailed summary of the literature is provided in Appendix E.

\subsection*{8.5.1 Availability of evidence}

As outlined above, there is very limited evidence available to enable us to draw any robust conclusions regarding the long-term impact of early intervention for children with visual impairment and in particular, measure likely outcomes across the population or assign probabilities to improvements. However, studies that have examined the efficacy and effectiveness of early interventions for children with visual

\textsuperscript{232} Deitz, S.J. (1993). Early services for young children with visual impairment: from diagnosis to comprehensive services. Infants and Young Children, 6(1), pp 68-76.

impairment establish a very solid foundation for improved outcomes. Indeed, it is plausible that early intervention that aids the child in developing compensatory skills to mitigate the impact of their impairment, and importantly, addresses the key risks that could adversely impact that child’s development, could yield material improvements in long-term outcomes, particularly if no other impairments are present.

In the absence of robust outcomes studies, we can only hypothesise as to possible long-term impacts. As with most disabilities, the outcomes are also likely to vary between individuals. However, based on the above, achieving positive long-term outcomes from early intervention for children with visual impairment is considered plausible. As there is an absence of robust Australian evidence to confirm this hypothesis this will need to be addressed by future research.

8.5.2 Education

Base case

United States Federal agencies conducted several national surveys during the mid-1990s under the National Health Interview Survey on Disability (NHIS) project. The purpose of this exercise was to gain an increased understanding of the impact of various disabilities on a range of measures, including education and employment outcomes.

The results recorded in the NHIS project with regards to educational attainment are provided in Table 30.

Table 30 Educational attainment levels of people with severe visual impairment compared to the non-impaired

<table>
<thead>
<tr>
<th>Health status</th>
<th>Less than HS Grad</th>
<th>HS Grad or some college</th>
<th>College Grad or more</th>
</tr>
</thead>
<tbody>
<tr>
<td>With severe visual impairment</td>
<td>35%</td>
<td>54%</td>
<td>11%</td>
</tr>
<tr>
<td>Without severe impairments</td>
<td>14%</td>
<td>62%</td>
<td>24%</td>
</tr>
</tbody>
</table>


The National Longitudinal Transition Study (NLTS) tracked the experiences of a large number of secondary school students with disabilities across the United States in the late 1980s and early 1990s. The NLTS-2, which was completed in 2009, recorded positive results in relation to the educational attainment levels achieved by young people with visual impairment, with 78% of the young people reporting as having
attended post-secondary education programs. The most commonly attended program was two-year and community colleges (56%) followed by four-year colleges (44%).

The above results are supported by other studies, as reported by Nagle (2001).

Table 31 Educational attainment levels of people with visual impairment compared to non-impaired individuals

<table>
<thead>
<tr>
<th>Source</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>US Department of Education</td>
<td>• High school dropout rates for students with severe visual impairment reported at 17% compared to 30-50% for students with other disabilities</td>
</tr>
<tr>
<td>(1999)</td>
<td>• 30% of students with visual impairment graduated from high school with a standard diploma</td>
</tr>
<tr>
<td>Blackorby &amp; Wagner (1996)</td>
<td>• 70% of youths with visual impairment graduated from high school with either a standard diploma, a modified diploma or a certificate of completion</td>
</tr>
<tr>
<td></td>
<td>• 3 to 5 years after they had left school, 57% of students with visual impairment had attended tertiary education institutions</td>
</tr>
<tr>
<td>Wolfe, Roessler &amp; Schriner</td>
<td>• Of students with visual impairment, 6% had graduated from two-year colleges, 15% from four-year colleges and 33% had participated in post-baccalaureate training</td>
</tr>
<tr>
<td>(1992)</td>
<td></td>
</tr>
<tr>
<td>O’Day (1999)</td>
<td>• Out of 20 adults with visual impairment who were unemployed, 15 had attended some form of tertiary education institution, with 6 having at least a college degree</td>
</tr>
</tbody>
</table>

At least in the United States, educational outcomes for children with visual impairment have been reasonable. However, we have no data for Australia.

Importantly, we also have no data on the extent to which children with visual impairment require special education services, that is, they either need to attend a special school or attend a mainstream school but require additional support.

Estimating potential benefits

We have no specific data linking early intervention for children with visual impairment to education outcomes. Accordingly, we can only hypothesise as to the possible benefits.

As is stated in section 3.2, the additional per person cost of providing special education services to students with disabilities is estimated at $15,367 per annum. If:

- in the absence of early intervention, a child with visual impairment would have needed to attend a special school; and
- early intervention results in a material improvement in outcomes for that child to the point where they can attend a mainstream school with our without support;


or,

- in the absence of early intervention, a child with visual impairment would have needed to attend a mainstream school with support; and

- early intervention results in a material improvement in outcomes for that child to the point where they can attend a mainstream school without support,

all or part of this cost is avoided and therefore represents a benefit from early intervention.

If the entire cost is avoided, over 12 years of schooling, the total benefit (in Present Value terms) is estimated at $153,000 using a discount rate of 3% (base case) and $128,800 using a discount rate of 6%.

This estimate is considered to be the upper bound estimate for the benefits of early intervention in relation to the reduction in special education costs. The actual benefits for an individual are likely to lie between $0 and $153,000, as rather than completely negating the need for special education services, early intervention may reduce the intensity of special education services required for a child (i.e. the actual annual benefit may be some portion of the estimate of $15,367).

We have no data to estimate the cost savings that may be realised and in practice, this will vary for each child. In the absence of this data, we could take the mid-point (that is, assume that 50% of the costs are avoided), recognising that the actual cost savings for a child could be higher or lower than this.

There may also be other benefits for the child in attending a mainstream school that have not been captured here.

**8.5.3 Improved employment outcomes**

*Base case*

Despite reasonable educational outcomes, a difficulty in obtaining competitive employment is one of the most significant impacts of visual impairment. This leads to a loss of production and therefore a cost associated with visual impairment. Several studies and surveys have assessed the impact of severe visual impairment on employment outcomes. These are summarised in Table 32.

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### Table 32  Studies on level of unemployment in people with visual impairment

<table>
<thead>
<tr>
<th>Source</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kirchner, C., Schmeidler, E. &amp; Todorov, A. (1999).</td>
<td>• The employment rate reported for people aged 18 to 69 years in the US with no serious impairments was 77%, compared to only 42% for people with serious visual impairment. 55% of people with severe visual impairment were not included in the labour force (that is, are not considered to be employed or looking for employment), compared to 20% for people with no serious impairments.</td>
</tr>
<tr>
<td>Houtenville, (2003)</td>
<td>• Based on 1983-96 data, employment rate among males reported as being blind in both eyes was 49.4% (compared to 88.8% for non-impaired working-age males) • Males who reported visual impairment other than being blind in both eyes had an employment rate of 82.3% • Employment rate for individuals blind in both eyes aged 25-61 years of 28.2%</td>
</tr>
<tr>
<td>Turpin, et al (1997)</td>
<td>• Among 18-64 year olds with severe visual impairment, labour force participation rate was 30.1%</td>
</tr>
<tr>
<td>Kirchner, et al (1999)</td>
<td>• Based on 1994-1995 NHIS data, employment rate of 54% among individuals aged 18-54 years with severe visual impairment</td>
</tr>
<tr>
<td>Fawcett (1996)</td>
<td>• Labour force participation rate for working age individuals with visual impairment in Canada in 1991 estimated at 45.6%</td>
</tr>
<tr>
<td>American Foundation for the Blind (2006)</td>
<td>• 32% of individuals aged 18-69 years who are legally blind are employed (with a significant proportion of employed individuals being underemployed)</td>
</tr>
<tr>
<td>Shaw, Gold &amp; Wolfe (2007)</td>
<td>• 29% of 328 Canadian youths with visual impairment were employed (36% employment for youths with low vision and 19% employment for blind youths)</td>
</tr>
<tr>
<td>National Longitudinal Transition Study 2 (2009)</td>
<td>• 43% of the out of high school youth with visual impairment were employed at the time of the survey with 35% of those without employment stating that they had been searching for a job</td>
</tr>
<tr>
<td>Clements, B., Douglas, G. &amp; Pavey, S. (2011)</td>
<td>• Focussed on people who were registered as blind or visually impaired in Britain. Results showed a clear difference in employment status between visual impairment and general population of working age – ¾ of general population in work, with only 1/3 of those with visual impairment</td>
</tr>
</tbody>
</table>

As highlighted by Clements, Douglas and Pavey, employment outcomes are influenced by a number of other factors, including housing tenure, educational attainment, the severity of visual impairment and the presence of additional disabilities. They also noted that some barriers to employment are presented by employers, for example, attitudes towards disability and/or physical layout. Access Economics highlight some of the main barriers to employment for people with visual impairment as being:

- difficulties completing paper forms;
- problems accessing online applications through specialist technology;
- difficulties reading print material provided at interviews or in assessment centres;

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- the requirement for a drivers licence to comply with selection criteria; and
- encountering employers who had preconceived ideas about the capabilities (or disabilities) of the applicant.

Many people with visual impairment are productive members of the workforce. However, the above evidence suggests that it is plausible that a person may have difficulty obtaining a job at all, or will have difficulty obtaining a job that fully utilises their skills and capabilities.

Economy-wide cost estimates

In 2009, Vision 2020 Australia commissioned Access Economics to update its 2004 ‘Clear Insight’ report, which assessed the economic impact and cost of vision loss in Australia.\(^{239}\) The focus of this report was on people aged over 40, recognising the significant number of people who acquire some form of visual impairment as they age. It will therefore include people who have acquired visual impairment later in life (which is not of direct interest to our study), as well as people who have had visual impairment since childhood.

Access Economics estimated the costs relating to lost earnings (productivity) associated with visual impairment at $2.3 billion in 2009. This reflected losses due to lower than average employment rates (adjusted for age), losses from premature mortality, and the costs of employers bringing forward employee search and hiring costs due to premature mortality.

Impact of early intervention

As outlined above, there have been no longitudinal studies conducted that have assessed the impact of early intervention on the employment outcomes for individuals with visual impairment. Again, we can therefore only hypothesise in relation to possible outcomes and benefits.

To the extent that early intervention is able to materially improve the development path for a child with visual impairment, and therefore improve their educational performance as well as their ability to function in different environments, it is plausible that early intervention could lead to improved employment outcomes for people with visual impairment.

There are a number of caveats to this assumption. First, there are other aspects of functioning that will impact educational attainment and (or) employment outcomes.

\(^{239}\) Access Economics (2010).
Second, the outcomes achieved for different individuals will vary, reflecting the variations in the nature and extent of the impairment as well as the child’s response to early intervention. Third, employment outcomes are influenced by factors external to the individual. As outlined above, for people with visual impairment some of the barriers may be created by the environment, including the attitude of potential employers (and we would expect this to be an issue across all disabilities).

**Estimating potential benefits**

Section 3.3 contains the estimates and parameters used to estimate the productivity benefits associated with improved employment outcomes from early intervention. The assumptions applied to full-time employment are:

- based on ABS data, an average annual salary for all employees of $53,040 ($65,052 for males and $41,600 for females); and

- based on the parameters in section 3.3, a lifetime estimate for total earnings across all employees (in Present Value terms) of $1.14 million ($1.398 million for males and $0.894 million for females).

In the event that early intervention enables an individual to obtain part-time employment at the ABS rate for average annual earnings, the corresponding estimates are as follows:

- average annual earnings for all employees of $33,150 ($40,658 for males and $26,000 for females). We have based this on 62.5% of full-time earnings; and

- lifetime estimate for total earnings across all employees (in Present Value terms) of $712,000 ($874,000 for males and $559,000 for females) using a 3% discount rate.

Early intervention may not necessarily enable all individuals with visual impairment to obtain employment at a rate (salary) that is commensurate with the entire population. At minimum, a person’s salary (in competitive employment) will be based on the minimum wage. The benefit associated with this outcome, as per section 3.3, is $30,644 per annum or $0.658 million in Present Value terms over a 35 year working life. The corresponding estimates for an individual that is able to secure part-time employment at the minimum wage are $19,153 per annum or $412,000 over a 35 year working life.

These estimates represent the benefit that will be achieved if early intervention enables an individual with visual impairment - who would otherwise have been unemployed - to obtain competitive employment. They can also be used to estimate the benefits of reducing underemployment, for example, where a person who would have otherwise only earned the minimum wage can secure a job at the average wage.
Table 33 presents the annual and lifetime benefits relating to gains in productivity as discussed above. We have also shown the sensitivity of the lifetime benefit estimates to a 6% discount rate instead of our base case assumption of 3%.

Table 33  Potential productivity benefits resulting from early intervention per person

<table>
<thead>
<tr>
<th>Benefit</th>
<th>Annual benefit ($/yr)</th>
<th>Lifetime benefit – 3% discount rate</th>
<th>Lifetime benefit – 6% discount rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Obtain full-time employment at average wage</td>
<td>53,040</td>
<td>1,140,000</td>
<td>769,000</td>
</tr>
<tr>
<td>Obtain part-time employment at average wage</td>
<td>33,150</td>
<td>712,000</td>
<td>481,000</td>
</tr>
<tr>
<td>Obtain full-time employment at minimum wage</td>
<td>30,644</td>
<td>658,000</td>
<td>444,000</td>
</tr>
<tr>
<td>Obtain part-time employment at minimum wage</td>
<td>19,153</td>
<td>412,000</td>
<td>278,000</td>
</tr>
</tbody>
</table>

Note: Part-time estimates are generated based on 25 hours per week (i.e. 62.5% of full-time rate). For presentation purposes the estimates have been rounded.

Based on these estimates, if a person would have otherwise been unemployed but obtains competitive employment as a consequence of improved outcomes achieved as a direct result of early intervention, this could increase economic productivity by $412,000 over their working lifetime (based on part-time employment at the minimum wage). A more optimistic assumption is that they gain full-time employment at the average wage, which would result in an increase in economic productivity of $1.14 million. They may secure employment at a rate above the average wage.

As outlined above, we can also use these estimates to measure the potential benefits of reducing underemployment. For example, if a person who would have otherwise only earned the minimum wage can secure a job at the average wage, the productivity benefit will be based on the difference between their earnings based on the average wage and their earnings based on the minimum wage.

As discussed in section 3.3, there are a number of important qualifications to this approach. In particular, it assumes that the employment of the person results in a net increase in productivity in the economy, which equates to their salary.

As outlined above, the actual outcomes will vary anywhere along this spectrum. Some people with visual impairment will have gained employment without early intervention. Others who have been through an early intervention program may still not gain competitive employment. However, the life outcomes for these individuals and their families may still be improved in other areas.
8.5.4 Living independence

Base case

In a study by Halpern, young people with visual impairment were found to have the highest rates of living independently after graduation from high school of all the disability categories, with 17.2% living independently less than two years after high school (compared to 13% across all disabilities). The results were the same three to five years out of secondary school, with 46.4% of individuals with visual impairment living independently compared to 37.4% of all youths with disabilities. However, these rates are still well below the rate of residential independence for young people in general, which was estimated at 60%.

The National Longitudinal Transition Study 2 (2009), which looks at post high school outcomes for youth with disabilities in the US, reported that the proportion of young people with visual impairment living independently or semi-independently were 19% and 18% respectively. A large majority (over 80%) of these individuals were satisfied with their living situation.

Economy-wide cost estimates

Access Economics estimated the costs of informal care of people with visual impairment in Australia in 2009 using data from the ABS’ 2003 SDAC. This identified 40,300 informal carers (primary and non-primary) of people who had a disease of the eye and adnexa. Of these informal carers, 39,400 were aged over 15 years. The weighted average hours of primary care provided to people with an eye disease in 2003 was 24.4 hours per week, with an average of five hours of non-primary care provided. Using the opportunity cost method, the total estimated economic cost to the Australian economy in 2009 was $251 million.

As outlined above, these estimates would include the costs of caring for people who have acquired visual impairment since childhood, which is not within the scope of our study.

Impact of early intervention

There is no robust evidence available that enables us to directly estimate the impact of early intervention for children with visual impairment on their ability to live independently as adults. While the early intervention strategies discussed above could certainly be seen to improve education and potentially employment outcomes, we would be cautious in ascribing any relationship between these strategies and changes in living independence. In any case, as outlined above, some of the research suggests that people with a visual impairment already have higher rates of living independence compared to other disabilities, although this rate is still below the average of the general population.

It is also recognised that living independence may also require aids and/or home modifications. As the need for these aids and/or home modifications is unlikely to be impacted by early intervention, they will not be considered further here.

Estimating potential benefits

The benefits of improvements in living independence could manifest in one or both of the following:

- reduction in the cost associated with formal services provided (i.e. accommodation support, community access and support, respite care, etc.); and/or
- reduction in informal care required.

Formal care

As stated in section 3.4.1, it has not been possible to generate estimates of the costs incurred in providing formal care services for all of the specific disabilities. However, it is possible to estimate the cost of services provided to individuals across all disabilities. It is also considered reasonable to conclude that people with visual impairment could require formal care services.

The estimated cost per person per year, as well as the estimated lifetime costs, is provided in Table 34. Again, we have estimated the lifetime benefits assuming a discount rate of 3% (base case) and 6%.
Table 34  Per person expenditure on disability support services  

<table>
<thead>
<tr>
<th>Service</th>
<th>Annual cost ($/person)</th>
<th>Cost over 20 yrs @ 3%</th>
<th>Cost over 40 yrs @ 3%</th>
<th>Cost over 20 yrs @ 6%</th>
<th>Cost over 40 yrs @ 6%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accommodation support</td>
<td>67,101</td>
<td>998,300</td>
<td>1,551,000</td>
<td>769,600</td>
<td>1,009,600</td>
</tr>
<tr>
<td>Community support</td>
<td>6,740</td>
<td>100,300</td>
<td>155,800</td>
<td>77,300</td>
<td>101,400</td>
</tr>
<tr>
<td>Community access</td>
<td>11,429</td>
<td>170,000</td>
<td>264,200</td>
<td>131,100</td>
<td>172,000</td>
</tr>
<tr>
<td>Respite</td>
<td>9,937</td>
<td>147,800</td>
<td>229,700</td>
<td>114,000</td>
<td>149,500</td>
</tr>
<tr>
<td>Employment support</td>
<td>5,469</td>
<td>81,400</td>
<td>126,400</td>
<td>62,700</td>
<td>82,300</td>
</tr>
</tbody>
</table>

Note: Data does not cover all expenditure on services by people with disabilities – only relates to services funded under the CSTDA and National Disability Agreement. For presentation purposes estimates have been rounded.


As Table 34 shows, to the extent that a person with visual impairment is a consistent user of formal care services, and early intervention reduces their need for these services, the benefits could be up to $1.55 million (this is the avoided cost of long-term accommodation support). Caution must be exercised in making any generalisations from this data, however, given that the nature and extent of service use and outcomes achieved will vary between individuals. For example, for some individuals who have received early intervention, they may still need to rely on formal services, however the intensity of their service use may be reduced, which would still yield a cost saving.

Informal care

In relation to informal care, as discussed in section 3.4.2, we are applying two approaches to estimating the potential benefits of early intervention – the opportunity cost method and the replacement cost method. In the absence of any specific data on the impact of early intervention on informal care, we can only hypothesise on possible outcomes. For example, Table 35 identifies three scenarios, ranging from a small reduction to a significant reduction, and shows the cost impact under each approach.

Table 35  Potential improvement scenarios in terms of informal care provided

<table>
<thead>
<tr>
<th>Improvement scenario</th>
<th>Opportunity cost approach</th>
<th>Replacement cost approach</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Impact</td>
<td>Consequence</td>
</tr>
<tr>
<td>Small (e.g. reduction of 5 hrs of informal care per week)</td>
<td>Will not necessarily improve carer’s ability to maintain employment</td>
<td>No productivity impact</td>
</tr>
<tr>
<td>Moderate (e.g. reduction of 15 hours of informal care per week)</td>
<td>Carer may be able to secure a part time job</td>
<td>Increase in productivity based on part-time contribution</td>
</tr>
<tr>
<td>Significant (e.g. reduction of 30 hours)</td>
<td>Carer may be able to secure full-time job</td>
<td>Increase in productivity based on</td>
</tr>
</tbody>
</table>
As can be seen from Table 35, the potential benefits attributable to early intervention will vary significantly depending on the approach that is adopted. For example, consider the scenario in which the amount of informal care required is reduced by five hours per week as a result of early intervention. Under the opportunity cost approach, this would not result in any benefits being estimated due to the absence of a productivity impact (as reducing the amount of informal care provided by only five hours per week is unlikely to allow the carer to obtain employment). Alternatively, under the replacement cost approach, the benefit will be equal to the imputed market rate for informal care multiplied by five hours per week.

The assumptions to be applied to estimating the benefits from reduced informal care are set out in section 3.4.2 and are as follows:

- opportunity cost approach: average weekly earnings of $944 or $49,105 per annum for full time employment and $30,691 for part time employment (part time estimate based on 25 hours per week); and
- replacement cost approach: a value of $31.81 per hour of care.

Table 36 takes the three potential improvement scenarios from Table 35 and estimates the annual benefit per person resulting from early intervention under the two approaches.

<table>
<thead>
<tr>
<th>Improvement scenario</th>
<th>Annual benefit</th>
<th>Opportunity cost approach</th>
<th>Replacement cost approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small (5 hr/week reduction)</td>
<td>-</td>
<td>$8,300</td>
<td></td>
</tr>
<tr>
<td>Moderate (15 hr/week reduction)</td>
<td>$30,700*</td>
<td>$24,800</td>
<td></td>
</tr>
<tr>
<td>Significant (30 hr/week reduction)</td>
<td>$49,100</td>
<td>$49,600</td>
<td></td>
</tr>
</tbody>
</table>

* This estimate is based on an individual with a part time job working 25 hours per week (i.e. 62.5% of the estimate for full-time employment).

Note: For presentation purposes the estimates have been rounded.

Over a 35 year working life, the total benefits (in Present Value terms) are as follows:

- under the opportunity cost approach:
  - $659,700 from a moderate reduction in informal care requirements ($445,100 using a discount rate of 6%); and
- $1.055 million from a significant reduction in informal care requirements ($711,900 using a discount rate of 6%);

under the replacement cost approach:
- $178,300 from a small reduction in informal care requirements ($120,300 using a discount rate of 6%);
- $532,900 from a moderate reduction in informal care requirements ($359,600 using a discount rate of 6%); and
- $1.066 million from a significant reduction in informal care requirements ($719,100 using a discount rate of 6%).

The results presented above demonstrate the wide range of potential benefits resulting from a reduction in informal care through early intervention. As outlined above, many people with a visual impairment are able to live reasonably independently, and accordingly will not require significant hours of informal care per week. It is also difficult to ascertain the likely extent to which early intervention might directly result in improvements in living independence.

**8.5.5 Improved quality of life**

**Base case**

As previously stated in section 3.6, the focus of this study in terms of assessing quality of life impacts has been limited to YLD (that is, it does not focus on premature mortality). For visual impairment, this is measured based on a disability weighting of $0.17 (see Table 3). This disability weighting is then applied to the estimate for the VOLY of $288,965 (June 2011 dollars) to produce an annual per person cost of $49,124. This estimate represents the base case annual cost of a reduction in quality of life for a person with visual impairment.

**Economy-wide cost estimates**

Access Economics produced an economy-wide estimate of the cost of the reduction in quality of life arising as a consequence of visual impairment for people over 40 years of age in Australia in 2009.\(^{243}\) This includes both morbidity and premature mortality. In 2009, the total DALYs attributed to vision loss in Australia was 58,150. Of these, 51,409 DALYs related to morbidity. The estimated cost of this was $9.4 billion in 2009.

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\(^{243}\) Access Economics (2010).
Impact of early intervention

The impact of a disability on quality of life is determined by a range of factors including physical and mental health issues, living independence, mobility, etc. While there is a lack of longitudinal studies assessing the impact of early intervention on these factors for individuals with visual impairment, we consider that, based on the evidence that is available, some improvement is plausible. Again, we also recognise that the availability of aids and other assistance (that may be required regardless of whether or not a person received early intervention as a child) could also impact quality of life.

The benefits from improvements in quality of life as a result of early intervention can be estimated by assessing the potential impact on the disability weighting for individuals with visual impairment under different scenarios. It is recognised that scenarios are hypothetical.

Estimating potential benefits

As stated in section 3.6.1, the disability weighting for visual impairment is 0.17. If quality of life improves, this weighting will be reduced. Three reductions were applied to this weighting to assess the potential benefits of early intervention in terms of quality of life – a conservative reduction of 10% (reduces the disability weighting by 0.017), a significant reduction of 30% (reduces the disability weighting by 0.051), and a ‘mid-point’ estimate of 20% (reduces the disability weighting by 0.034). There is no evidence available to support the percentage reductions. The intention is to show what the benefit might be if such improvements were realised.

These reductions were applied to the VOLY ($288,965) to derive an estimate for the benefit associated with the improvements in quality of life potentially achievable through early intervention. The annual per person benefits estimated were as follows:

- $4,912 under the conservative scenario
- $9,825 under the median (or mid-point) scenario
- $14,737 under the significant improvement scenario.

The lifetime benefits were estimated over 20 and 40 years of adult life, using discount rates of 3% (base case) and 6%.
Table 37  Potential lifetime benefits from improvements in quality of life per person

<table>
<thead>
<tr>
<th>Improvement scenario</th>
<th>20-year benefit</th>
<th>40-year benefit</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>3% disc. rate</td>
<td>6% disc. rate</td>
</tr>
<tr>
<td>Conservative</td>
<td>73,000</td>
<td>56,300</td>
</tr>
<tr>
<td>Median</td>
<td>146,200</td>
<td>112,700</td>
</tr>
<tr>
<td>Significant</td>
<td>219,300</td>
<td>169,000</td>
</tr>
</tbody>
</table>

Note: For presentation purposes estimates have been rounded.

Based on the scenarios modelled above, the conservative scenario of a 10% improvement in quality of life (or a 10% reduction in the disability weighting) for 20 years of adult life produces a present value benefit of $73,000. A more optimistic scenario could yield benefits of $219,300 over the same time period. The longer these improvements are maintained throughout adult life, the higher the benefits.

This shows that if even small improvements are achieved (and sustained for some period), the benefits are significant. Recognising the issues involved in reliably measuring quality of life impacts (as discussed in section 3.6), even relatively small improvements in this metric alone could outweigh the cost of early intervention.

8.5.6 Improved health outcomes

Base case

We have no specific information on the incremental healthcare costs incurred by people with visual impairment, particularly in relation to the costs that are incurred by people that are borne with a visual impairment (compared to people who develop visual impairment later in life).

Economy-wide cost estimates

Access Economics produced an economy-wide estimate of the healthcare costs incurred by people with visual impairment in Australia aged over 40 in 2009. Access Economics (2010). This will include the costs incurred by people who developed visual impairment later in life and will also reflect the costs of treating conditions such as cataracts and glaucoma. Total allocated expenditure was $2.58 billion, which includes: hospital and out of hospital care, pharmaceuticals, aged care, optometry, research and other health professionals.

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244 Access Economics (2010).
Impact of early intervention

We have no evidence linking early intervention for children with visual impairment to healthcare outcomes. Despite the plausibility of improvements in outcomes across a range of areas, we do not consider that we have a sufficient evidence base to draw a direct linkage between early intervention and healthcare outcomes. For example, if it improved functions such as balance and motor skills, it could reduce the occurrence of accidents and injury. However, we do not have specific evidence linking these outcomes to early intervention and accordingly, we have not sought to ascribe any benefits here.

8.5.7 Improved quality of life for families

As outlined in section 2, there is considerable evidence suggesting that caring for a child or adult with a disability, including a child with visual impairment, could have a significant impact on the family. While some of the costs associated with this impact are accounted for under the costs of informal care, there are also other costs including the impacts of higher levels of stress in the family environment (e.g. marital breakdown).

As previously stated in section 3.7, there is currently no accepted methodology available for estimating these costs and as a result they have not been included in this study. However, the benefits from early intervention in terms of improving family quality of life are considered to be potentially significant and therefore should not be ignored.

8.6 Summary of benefits from early intervention

In summarising the results of this assessment it is firstly necessary to reiterate the absence of robust data on long-term outcomes for children with visual impairment that receive early intervention. However, we consider that it is reasonable, based on the evidence that is available, to conclude that early intervention does have the potential to generate material benefits.

The benefits of early intervention will vary between children with visual impairment. These benefits are subject to a number of factors, including:

- the nature and extent of the child’s impairments before intervention
- their age of referral to an intervention program
- the nature and intensity of the intervention received
• the child’s response to the intervention
• the influence of other environmental and contextual factors
• the presence and influence of comorbid conditions.

Accordingly it is not appropriate to provide point estimates of the total benefits or even a potential range of outcomes. The ability to provide such estimates would be improved by robust long-term outcome studies as this would provide evidence in relation to the early intervention strategies that work best for children with visual impairment under particular conditions.

In section 9 we hypothesise a range of potential scenarios for a child with a disability that has received early intervention. This recognises the wide spectrum of outcomes that could be observed between different disabilities and for any group of children with the same disability. We also recognise that the costs of early intervention can vary according to the nature of the program and the needs of the child and the family.

These scenarios hypothesise different combinations of outcomes, recognising that the outcome achieved in each area must be referenced to the outcomes that the child would otherwise have achieved in the absence of early intervention. Any of these outcomes is considered plausible for a child with visual impairment, having regard to the variables listed above. However, we cannot ascribe any probabilities to any of these scenarios being achieved.

Overall, this shows that early intervention for children with a visual impairment has the potential to generate significant positive economic benefits. Apart from the fact that this does not capture the full spectrum of outcomes that may be achievable, it is also important to remember that there are also other benefits that have not been quantified, such as improvements in the quality of life for families. Those benefits alone may be material.
9 Benefit-cost ratios

9.1 Methodology

The preceding chapters have explored the potential benefits of early intervention in key life outcomes, being education, employment, living independence and quality of life. Healthcare benefits were not assessed in detail for any of the disabilities. While it was acknowledged that early intervention may result in benefits for children with Cerebral Palsy, there was insufficient evidence available for us to be able to quantify the benefits. For the other four disabilities, it was difficult to postulate any link between early intervention and improvements in healthcare outcomes.

What is clearly evident from our analysis is that outcomes can vary considerably between disabilities and for any group of children with the same disability. This is particularly the case for ASD, Cerebral Palsy and Down syndrome given the multi-dimensional nature of these conditions (variation can also be expected for hearing impairment and visual impairment however the range may not be as wide, especially in the absence of comorbid conditions).

In the absence of data on the long-term outcomes for children with disabilities that have received early intervention we think that a reasonable starting point for evaluating the costs and benefits is by hypothesising alternative scenarios that are considered plausible based on what is known about early intervention for children with disabilities. These scenarios consider combinations of outcomes in the key life areas described above. This is considered important because many of these outcomes are related. For example, educational outcomes will influence employment. An improvement in quality of life could occur independent of these outcomes, but could also arise as a consequence of improved health, educational outcomes, living independence and/or employment prospects.

We do not consider that it is realistic or appropriate to present a single overall range of outcomes. A key reason for this is that the outcomes will depend on the individual’s level of functioning prior to intervention, as well as their response to intervention (apart from other factors). For example, we do not consider it appropriate to specify a maximum BCR by simply summing all of the maximum BCRs for each area, as this is effectively assuming that:

- in the absence of early intervention, the child would have achieved the worst possible outcome (that is, the maximum possible cost would have been incurred in each area); and

- following intervention, the child achieves the best possible outcome.
While we are not necessarily ruling this out, we currently have no evidence to support it. Based on the evidence that is available, the more likely outcomes will lie somewhere in between the child’s starting point and the maximum potential benefit achievable from early intervention.

Instead, we therefore postulate different scenarios that could be achieved through early intervention, ranging from a small improvement in quality of life only, through to improved outcomes in a number of areas. If a benefit is reflected in a particular scenario it means that there has been a positive change in an outcome as a consequence of early intervention. The way we have captured this is that:

- educational outcomes could be improved by:
  - a child that would have attended a special school being able to attend a mainstream school, with or without support;
  - a child that would have attended a mainstream school with support, being able to attend that school without support;

- employment outcomes could be improved by:
  - a person who would otherwise have been unemployed secures a full-time or part-time job;
  - a person who would have been employed at the minimum wage secures a full-time or part-time job at the average wage;
  - a person who would have been employed on a part-time basis (that wants full-time work), secures a full-time job;

- living independence could be improved by:
  - reduced reliance on formal care services; and/or
  - reduced reliance on informal care.

We expect that positive outcomes would also result in some improvement in quality of life. We have captured this via changes to the disability weight. These consequent changes are hypothetical only as we do not have the data to re-estimate disability weights under different scenarios.

We have also postulated uniform outcomes in terms of changes in the disability weight. It is important to consider these changes in the context of the average disability weight for each disability. For example, a reduction in the disability weight of 0.1 is around 15% to 20% of the average disability weight for Cerebral Palsy, autism and
Down syndrome (in the case of the latter, for someone aged over 40). This is a material improvement. For visual impairment, which has a disability weight of 0.17, the improvement is over 60%, which is major.

It is important to recognise that if a change is not assumed to occur under a particular scenario, it does not mean that the ‘base case’ scenario is an adverse outcome. For example, if a scenario does not assume any change to employment outcomes, this simply means that there is no change in that outcome. It does not imply that the person would otherwise have been employed or unemployed. This focus on changes that are the direct consequence of intervention is fundamental to an incremental analysis.

We have intentionally avoided estimating BCRs for each disability. This is because we think that any reported differences in BCRs could be misinterpreted if they are not considered within the context of the supporting information provided.

Further, with the exception of visual impairment (where we have not been able to obtain any reliable estimates of the costs of early intervention), we have only sourced early intervention costs from one service provider in each disability category. While these estimates are considered a reasonable indication of the costs incurred, we recognise that different programs may involve different costs.

We have not been asked to assess the efficacy of the intervention model that each of those service providers delivers or how they compare against other models. For example, our estimate for autism is based on an intensive, integrated 35 hour week program delivered in a specialised centre. If we presented BCRs for autism based on the costs of this program, it could also be assumed that these same BCRs apply to other programs that could employ very different treatment models (including less intensive programs) – even if the costs of those other programs were not dissimilar. Such generalisations cannot be inferred.

Accordingly, while ‘averaging’ across the different disabilities masks some underlying variability, it also avoids any inferences being made regarding specific intervention strategies over others (including the costs of those strategies), noting that we have not been asked to assess the efficacy of specific intervention programs. In order to capture this potential variability we have subjected the BCRs to sensitivity analysis for different program cost estimates.

9.2 Scenarios

A large number of alternative scenarios could therefore be identified. We have examined eight possible scenarios, which are listed in Table 38.
We have specified scenarios that we consider are conservative. This reflects the evidence base that is available as well as the potential variability in outcomes between individuals. It also recognises that measurement methods in some of these areas are contentious, for example, valuing productivity gains or quality of life impacts. Critically, it also reflects the difficulties in isolating the impact of early intervention on long-term life outcomes, which is a significant challenge faced by the research community.

Our measurement timeframes are also conservative. For example, employment benefits are estimated over a maximum 35 year working life, which is the average, not maximum, working life for a person in Australia. We have also only measured quality of life benefits over adult life. This does not mean that improvements in quality of life for a child or adolescent do not have significant value.

### Table 38 Outcome scenarios for early intervention

<table>
<thead>
<tr>
<th>Scenario</th>
<th>Education</th>
<th>Employment</th>
<th>Living Independence</th>
<th>Quality of life</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Child who would have attended a special school can attend a mainstream school with support. We have captured this benefit as saving 50% of the incremental cost of special education.</td>
<td>No change</td>
<td>No change</td>
<td>Disability weight reduces by 0.02. The quality of life benefit is captured by applying that disability weight reduction to the value of a life year.</td>
</tr>
<tr>
<td>B</td>
<td>Child who would have attended a special school can attend a mainstream school with support. We have captured this benefit as saving 50% of the incremental cost of special education.</td>
<td>No change</td>
<td>Reduces informal care by 5 hours per week. As this is not captured under the opportunity cost method (as would not change carer's employment status), we have conservatively estimated the benefit as 50% of the replacement cost value.</td>
<td>Disability weight reduces by 0.05. The quality of life benefit is captured by applying that disability weight reduction to the value of a life year.</td>
</tr>
<tr>
<td>C</td>
<td>Child who would have attended a special school can attend a mainstream school with support. We have captured this benefit as saving 50% of the incremental cost of special education.</td>
<td>Person would have otherwise been unemployed and secures a part-time job at the minimum wage.</td>
<td>No change</td>
<td>Disability weight reduces by 0.1. The quality of life benefit is captured by applying that disability weight reduction to the value of a life year.</td>
</tr>
<tr>
<td>D</td>
<td>No change</td>
<td>No change</td>
<td>Person who would have otherwise had to live in a supported accommodation facility can live independently. We have assumed that they would still need some help, so have reduced these costs by 75% instead of 100%.</td>
<td>Disability weight reduces by 0.05. The quality of life benefit is captured by applying that disability weight reduction to the value of a life year.</td>
</tr>
<tr>
<td>E</td>
<td>No change</td>
<td>Person would have otherwise been unemployed and secures reduced reliance on informal carer by 15 hours per week. We have</td>
<td>Reduced</td>
<td>Disability weight reduces by 0.1. The quality of life benefit is captured by</td>
</tr>
</tbody>
</table>

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### 9.3 Results

We have assumed an ‘average’ total cost of early intervention of $80,000. As outlined below, we have also tested the sensitivity of our results to changes in this assumption, being total program costs of $60,000 and $100,000.

Results are presented assuming that the benefits are maintained over 20 and 40 years of adult life (employment benefits are truncated at 35 years of working life), using discount rates of 3% and 6%. The rationale for limiting the timespan for adult life assumptions was outlined above. This also further reflects the lack of evidence supporting the persistence of benefits throughout adult life. However, it is recognised that some benefits may persist over longer timespans. It certainly does not reflect any assumptions regarding the lifespan of a person with a disability. Table 39 presents the results if the program cost is $80,000 per child.

<table>
<thead>
<tr>
<th>Scenario</th>
<th>Education</th>
<th>Employment</th>
<th>Living independence</th>
<th>Quality of life</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Child who would have attended a special school can attend a mainstream school without support.</td>
<td>Person would have otherwise been unemployed and secures a full-time job at the average wage.</td>
<td>estimated this by taking the average of the replacement cost value and the opportunity cost value (assuming the carer is able to secure part time employment as a result of the reduction in care).</td>
<td>applying that disability weight reduction to the value of a life year.</td>
</tr>
<tr>
<td>F</td>
<td>Child who would have attended a special school can attend a mainstream school without support.</td>
<td>Person would have otherwise been unemployed and secures a full-time job at the average wage.</td>
<td>No change</td>
<td>Disability weight reduces by 0.1. The quality of life benefit is captured by applying that disability weight reduction to the value of a life year.</td>
</tr>
<tr>
<td>G</td>
<td>Child who would have attended a special school can attend a mainstream school without support.</td>
<td>No change</td>
<td>Reduced reliance on informal carer by 15 hours per week. We have estimated this by taking the average of the replacement cost value and the opportunity cost value (assuming the carer is able to secure part time employment as a result of the reduction in care).</td>
<td>Disability weight reduces by 0.1. The quality of life benefit is captured by applying that disability weight reduction to the value of a life year.</td>
</tr>
<tr>
<td>H</td>
<td>Child who would have attended a mainstream school with support can attend a mainstream school without support. We have captured this benefit as saving 50% of the incremental cost of special education.</td>
<td>Person would have been only able to secure a part-time job at the minimum wage and secures a full-time job at that wage.</td>
<td>No change</td>
<td>Disability weight reduces by 0.1. The quality of life benefit is captured by applying that disability weight reduction to the value of a life year.</td>
</tr>
</tbody>
</table>
### Table 39 BCRs of early intervention: EI program cost per child = $80,000

<table>
<thead>
<tr>
<th></th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
<th>G</th>
<th>H</th>
<th>I</th>
</tr>
</thead>
<tbody>
<tr>
<td>20 years</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3%</td>
<td>2.0</td>
<td>4.4</td>
<td>9.3</td>
<td>14.7</td>
<td>16.7</td>
<td>17.1</td>
<td>12.4</td>
<td>8.5</td>
<td>11.8</td>
</tr>
<tr>
<td>6%</td>
<td>1.6</td>
<td>3.5</td>
<td>7.3</td>
<td>11.4</td>
<td>12.9</td>
<td>13.4</td>
<td>9.7</td>
<td>6.6</td>
<td>11.6</td>
</tr>
<tr>
<td>40 years</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3%</td>
<td>2.6</td>
<td>6.3</td>
<td>13.4</td>
<td>22.9</td>
<td>25.3</td>
<td>24.5</td>
<td>18.3</td>
<td>12.4</td>
<td>15.4</td>
</tr>
<tr>
<td>6%</td>
<td>1.9</td>
<td>4.7</td>
<td>9.1</td>
<td>14.9</td>
<td>16.7</td>
<td>16.7</td>
<td>12.3</td>
<td>8.3</td>
<td>11.8</td>
</tr>
</tbody>
</table>

The results if the program cost is $60,000 per child are presented in Table 40.

### Table 40 BCRs of early intervention: EI program cost per child = $60,000

<table>
<thead>
<tr>
<th></th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
<th>G</th>
<th>H</th>
<th>I</th>
</tr>
</thead>
<tbody>
<tr>
<td>20 years</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3%</td>
<td>2.7</td>
<td>5.9</td>
<td>12.5</td>
<td>19.6</td>
<td>22.3</td>
<td>22.9</td>
<td>16.6</td>
<td>11.3</td>
<td>15.7</td>
</tr>
<tr>
<td>6%</td>
<td>2.2</td>
<td>4.6</td>
<td>9.7</td>
<td>15.1</td>
<td>17.2</td>
<td>17.8</td>
<td>13.0</td>
<td>8.8</td>
<td>15.4</td>
</tr>
<tr>
<td>40 years</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3%</td>
<td>3.5</td>
<td>8.4</td>
<td>17.8</td>
<td>30.5</td>
<td>33.7</td>
<td>32.7</td>
<td>24.4</td>
<td>16.5</td>
<td>20.5</td>
</tr>
<tr>
<td>6%</td>
<td>2.5</td>
<td>6.3</td>
<td>12.1</td>
<td>19.9</td>
<td>22.2</td>
<td>22.2</td>
<td>16.4</td>
<td>11.1</td>
<td>15.7</td>
</tr>
</tbody>
</table>

The results if the program cost is $100,000 per child are presented in Table 41.

### Table 41 BCRs of early intervention: EI program cost per child = $100,000

<table>
<thead>
<tr>
<th></th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
<th>G</th>
<th>H</th>
<th>I</th>
</tr>
</thead>
<tbody>
<tr>
<td>20 years</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3%</td>
<td>1.6</td>
<td>3.5</td>
<td>7.5</td>
<td>11.8</td>
<td>13.4</td>
<td>13.7</td>
<td>10.0</td>
<td>6.8</td>
<td>9.4</td>
</tr>
<tr>
<td>6%</td>
<td>1.3</td>
<td>2.8</td>
<td>5.8</td>
<td>9.1</td>
<td>10.3</td>
<td>10.7</td>
<td>7.8</td>
<td>5.3</td>
<td>9.2</td>
</tr>
<tr>
<td>40 years</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3%</td>
<td>2.1</td>
<td>5.1</td>
<td>10.7</td>
<td>18.3</td>
<td>20.2</td>
<td>19.6</td>
<td>14.6</td>
<td>9.9</td>
<td>12.3</td>
</tr>
<tr>
<td>6%</td>
<td>1.5</td>
<td>3.8</td>
<td>7.3</td>
<td>11.9</td>
<td>13.3</td>
<td>13.3</td>
<td>9.8</td>
<td>6.7</td>
<td>9.4</td>
</tr>
</tbody>
</table>

### 9.4 Interpretation

In the field of economics, BCRs of the magnitude observed above are substantial. Indeed, even if early intervention yields only a relatively small improvement in quality of life (Scenario A), the benefits still outweigh the costs. As outlined above, we have sought to make this analysis conservative. Apart from the assumptions noted previously, we would reiterate that it does not include costs such as improvement in the quality of life for families, which evidence suggests is a significant and material benefit of early intervention.
We must also reiterate that these are possible outcomes for a child. We have no data to assign any probabilities to the outcomes proposed above, or to extrapolate estimates across the population.

Most importantly, there is significant variability underpinning these outcomes, both between and within different types of disability. Not all children will benefit from early intervention. Some may achieve outcomes in excess of the estimates proposed above. Overall, however, there is uncertainty in relation to the outcomes, although we expect that this uncertainty will reduce as we progress further through the current generation of early intervention research.

If anything, if no other impairments are present the outcomes for children with visual and hearing impairment may be more stable and predictable. In particular, the evidence we have presented for hearing impairment (which is dominated by the provision of AVT for children who have received an amplification device) suggests a greater likelihood that any positive changes from early intervention will persist well into adult life.

It is also important to note that for these two disabilities, the baseline outcomes without early intervention will be higher than the baseline outcomes for the other disabilities (particularly for those with severe impairments). For example, a person with a hearing impairment who has a hearing device but received no intervention is still more likely to be able to get a job (although they may be underemployed). In this case, early intervention has the clear potential to enable that person to maximise their full potential, and perhaps secure a job that reflects the full extent of their skills and capabilities. This would have a significant impact on that individual in addition to benefiting the wider economy.
10 Conclusion

On the whole, robust data linking specific intervention strategies to long-term outcomes for children who have received early intervention is lacking. However, the efficacy and effectiveness studies that have been done suggest that positive outcomes are plausible. Rather than being required to prove the need for early intervention, the ‘second generation’ of early intervention research needs to target the development of an understanding with regards to which strategies work best for whom, and under what circumstances.

Despite the limitations in the evidence base, this initial analysis suggests that early intervention has the potential to generate positive and material benefits for children with disabilities and their families across the spectrum of disability types we have examined.

There is a broad spectrum of possibilities that reflect differences in the child, the family, the nature of the intervention, and the wider environment. This point was highlighted by Angela Tillmanns, the Chief Executive Officer of the Cerebral Palsy League in Queensland, as part of the Productivity Commission’s review of disability care and support:\(^{245}\)

> I think we've got to think about independence as a continuum. Independence isn't just paid employment. Independence can be a whole range of things. We see that with severities of cerebral palsy. There are some people that have such high levels of cerebral palsy and, coupled with other disabilities, really all they can do is just blink and have eye-gaze technology. As I said, that enables them to turn on and off their lights, choose their TV programs, start to communicate a little bit using the Internet. Even that brings greater dignity to a person and a greater quality of life.

It is important to note that it is neither realistic nor is it necessary to assume that early intervention obviates the need for ongoing support services for people with disabilities. This is reflected in our scenario analysis above, which hypothesises different outcomes in different areas. In any case, these ongoing costs have no impact on the BCRs presented in this report, as these costs would still have been incurred in the absence of early intervention. Early intervention may be able to reduce these costs, however this will not be the case for all.

Some barriers also continue to exist within the community itself. For example, a person with a disability may have difficulty securing a job not because of their own skills and

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capabilities, but due to a lack of understanding by potential employers regarding the nature and consequences of the disability, and/or because the work environment does not accommodate any unique needs that the person may have.

This report should be considered a starting point as part of the journey to understand the economic benefits and costs of early intervention. It is also important to recognise that our approach focuses on the economics of early intervention. This is only one aspect of the rationale for early intervention. There are other more significant considerations, such as the rights of the child (and the family) to be able to maximise their full potential.
A  Down syndrome

The following summarises our review of studies that have examined the efficacy and/or effectiveness of early intervention for children with Down syndrome. Some of the studies do not explore specific intervention strategies, however provide insights into early development that have implications for the design and implementation of these strategies.

A.1  General reviews of early intervention

Taylor notes that evidence shows that children with Down syndrome do not learn in the same manner as normally developing children, and that they have a different style of assimilating information. Down syndrome usually causes delays in physical, intellectual and language development. It is one of the main causes of cognitive delay in the population, with studies having shown that in early childhood children with Down syndrome can have standard cognitive scores at least two standard deviations below the mean. Taylor also describes impairments in language development and motor development.

This study looked at 81 children aged between 18 months and 6 years in the US who received early intervention from an integrated intervention program. It examined four developmental domains, being daily living skills (adaptive behaviour), motor skills, communication and socialisation.

The results showed that all domain and sub-domain scores increased between the first and second sub-periods of the study and then held steady. Overall, motor skills were significantly lower than the other three domains and socialisation was the highest scoring domain. Taylor’s study provides support for the need for early intervention from an early age and that this needs to be comprehensive (across domains).

Capone observes that our understanding of how an extra copy of chromosome 21 leads to the impairments it does (that is, the neurobiological consequences) is still limited. Studies that have examined the efficacy of early intervention for children with Down syndrome show benefits in terms of social adaptive functioning, however any improvements in cognitive functioning are often short-lived.

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It is necessary to ask why uniform cognitive benefits are not being observed. Capone suggests that this is for several reasons. First, children differ markedly in their neurobiological competence (within Down syndrome as well as compared to other children without Down syndrome). Second, there has been a failure to recognise the complex neurobehavioural syndromes that are often associated with Down syndrome and require different intervention strategies to succeed:248

A relatively common example of this phenomenon is when a child fails to achieve spoken language milestones and phonological competence despite attainment of cognitive skills and language comprehension skills capable of supporting complex speech (Kumin & Adams, 2000; Miller, 1988). These children require intervention strategies that emphasize vision based communication using sign or pictures to support symbol-based language development. Increasing the intensity of phonology based therapies alone, is too frequently met with poor success.

It is also noted that synaptic organisation in the cerebral cortex and early developmental function may not be delayed, but also aberrant in some children with Down syndrome.

Capone emphasises the need to understand where and why intervention works. It is suggested that its purpose is not necessarily to accelerate the pace of development. Instead, a key role is to support development by teaching specific strategies as neuromaturation proceeds, preventing prevent declines in development from occurring. It is also necessary to educate parents.

Capone considers that development-based therapies will become increasingly specialised and future treatments may focus on neurocognitive therapies:249

The future prospects for some degree of neurocognitive enhancement are realistic, but will require a shift in long-held beliefs about what is possible, as well as greater dialogue and interaction across disciplines, among professionals and academic centers specializing in clinical research for children with DS. As new knowledge emerges from clinical trials, either to support or refute the use of specific interventions, our ability to competently serve young children with DS will advance accordingly.

A study by Crombie and Gunn examined the effectiveness of early intervention for 41 children with Down syndrome in Brisbane.250 They examined two cohorts of children

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aged from 11 to 14. The first cohort was born in 1973/74, before early intervention became widely available. The second cohort (8 children) was born between 1976 and 78 (when early intervention was available).

Cohort 2 had ‘wide access’ to early intervention programs however the sample was not specifically selected on the basis of attendance at a particular program, for example, a number were enrolled in a study of children with Down syndrome at the University of Queensland. It was subsequently confirmed that this cohort participated in early intervention at an earlier age and for a longer duration. However, some members of Cohort 1 did participate in early intervention and some in Cohort 2 did not. They subsequently re-divided the groups based on the amount of early intervention received. They reclassified the group further based on ratings given to commencement age, frequency and duration of attendance (that is, they divided the groups based on the intensity of the intervention).

This study sought to examine the effectiveness of early intervention and also whether the ‘plateau effect’ of development holds in practice (for example, into adolescence). Measures included cognitive assessments and tests of adaptive functioning. Interviews with parents and caregivers were also conducted.

The results were disappointing. They found no significant differences in cognitive functioning. A plateau in cognitive functioning was not observed, with both cohorts showing progressive increases from 11 to 14. They also found no significant differences in adaptive functioning. Overall, significant variability in functioning was found within each cohort and it is not clear why this was the case.

The authors questioned why the early intervention group did not demonstrate improved functioning. For example, was it because of the nature of the program (which at the time, program was seen as a general form of stimulation rather than syndrome specific)? It was noted that programs did not focus on individual needs, raising the question of whether the ‘one size fits all’ approach is appropriate (which has been subsequently recognised in the literature).

They also questioned whether schools subsequently fail to build on foundations provided by early intervention. They also identified family factors as an important determinant. It would also appear to be essential to provide ongoing individualised support if early intervention is to produce long-term improvements in functioning. Despite the outcomes observed, Crombie and Gunn did not see this as questioning the fundamental benefits of early intervention:251

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There is a need for research into the most effective ways of providing such programs but this study suggests the need to recognise the futility of adopting a "one-shot" approach. Even effective early intervention will not pay off in the long term if we do not capitalise on its foundations.

We note that this is one of the few studies that have sought to assess the long-term benefits of early intervention (and it is Brisbane-based). However, it also highlights the potential issues with these studies, particularly at the current time. Apart from methodology and design issues, the individuals in the study participated in early intervention programs several decades ago. As is evident from this review, since this time, there has been significant progress made in understanding the development of children with Down syndrome and accordingly, the design and implementation of early intervention strategies. Hence, while long-term outcome studies remain a fundamental priority, they need to be on strategies that reflect contemporary theory and practice.

A paper by Nilholm reflects on the past and future issues for early intervention for children with Down syndrome.252 A number of early intervention evaluation studies have been published but there have been a number of methodological problems. Measurement of effects at a group level is another problem as it assumes equal effects on all participants.

Nilholm refers to reviews of studies of early intervention in Down syndrome, including a paper by Gibson and Harris (1988). These reviews have shown that follow-up studies of children in the early years have also yielded disappointing outcomes. However, the question should be why early intervention improves functioning in some areas but not others, for example, is it because certain developmental domains are not amenable to training, or is it because the programs are poorly designed.

Nilholm scrutinised the studies, taking into account the evaluation methods used. It was concluded that in relation to speech and language interventions, “there is hardly any evidence against the hypothesis that early intervention programs are beneficial as regards the language/speech domain.”253 The same line of reasoning applies in the area of gross motor domains, with most of the evidence appearing to support positive effects in this area (even though patterns not as clear as speech/hearing). It is noted that the question of long-term effects still needs to be addressed, and an understanding of the effectiveness of different strategies.

Hilholm remarked on the more recent trends on early intervention in Down syndrome. The first is the emphasis on the context of a child’s development. That is, the focus on skills training is being replaced by a focus on family and interactions. This in turn will require measures to be refined. It will also be necessary to identify characteristics of different groups of children, the child, and their family. Hilholm identifies some issues with this, as it is difficult to identify relative strengths and weaknesses of children with Down syndrome as a group, as well as for individual children. The question is then how these differences can be interpreted.

The other difficulty is the influence of the environment. Any differences observed in a group of children or a child with Down syndrome cannot necessarily be attributed to Down syndrome:254

In this perspective, controlled studies of children with Down syndrome imply the occurrence of a universal child with Down syndrome, i.e. a child whose characteristics could be mapped out separated from the prior transactions of the child with her/his environment.

It is proposed that it is necessary to satisfy three criteria to inform early intervention practices, being:

- the weakness as described is well established;
- it should meaningfully relate to the subsequent development of important behaviours/competencies; and
- training methods enhance the skill in question.

It will then be necessary to specify a new set of outcome variables that need to be contextualised. This context needs to somehow be written into early intervention evaluations. This in turn may mean that two types of studies are needed: the typical scientific studies based on larger samples, as well as case studies with detailed, descriptive accounts of individual children within a particular context.

Spiker and Hopmann reviewed the effectiveness of early intervention for children with Down syndrome.255 It is now recognised that children should be referred to an early intervention program as early as possible. This is facilitated by the ability to diagnose Down syndrome at or shortly after birth. The role of the family in development, and hence early intervention, is now also well recognised.

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Changes in medical treatment and social attitudes have also occurred (for example, the ability to deal with life threatening cardiac and other problems, which can now be addressed through surgery). Accordingly, people with Down syndrome now have a much longer life expectancy. These advances also mean that upper limits of achievement are not as clearly demarcated, encouraging children and families to target higher goals (which in itself produces challenges).

Early intervention can address the progressive decline in development that is commonly observed for children with Down syndrome. Another way to look at it is that by providing early experiences we can optimise their inclusion and participation in community activities and relationships. Interventions are also needed to increase the competencies of parents and caregivers, as well as providing emotional support and adjustment.

There is a growing body of research to understand the development of children with Down syndrome in areas such as information processing and cognitive ability, social behaviour and social interaction, parent-child interactions, language ability and development. The first generation research has confirmed the efficacy of early intervention. The chapter by Spiker and Hopmann provides a comprehensive review of this research.

Second generation research addresses more specific questions about strategies, goals child and family characteristics and outcomes. Considerably more research is needed in areas such as:

- the effect of program duration and intensity;
- the relationship between individual differences among children and families and program efficacy;
- effects of programs in integrated settings.

Key challenges for second generation research include:

- studies of program models;
- studies of how pre-linguistic communication is being addressed in early intervention programs, given the importance of language and communication skills;
- more differentiation of family characteristics and child factors as well as measures of program intensity and parent involvement;
- ongoing research on early intervention efficacy, as we must accurately represent the current state of knowledge and where studies are needed. Studies need to be
rigorously implemented and supported by early intervention practitioners and families;

- considering the tension between explicit caregiver behaviours that are contingent on specified child behaviours “and the desire to have youngsters with Down syndrome grow like flowers in the field amid all the other children.” Interventions are time intensive and specialised. The goals and realities of inclusion models must also be considered and more studies of these models are needed. As inclusion models develop further and more people become involved in interventions it is also important to ensure that skills required of professionals are not compromised; and

- more research on the effects of early intervention services on parents and families.

### A.2 Speech, language and communication

Aparico and Balana observe that the marked hypotony shown by babies with Down syndrome in the first year of life is a determining factor in their subsequent language development. As it impacts interaction with parents, the family environment can actually contribute towards deterioration in the language levels in babies with Down syndrome. Studies confirm that the family environment for children with disabilities such as Down syndrome is different compared to the environment for children with no impairments. Families can therefore benefit from early language treatment as it assists them in understanding the problem as well as helping them work more effectively with their child.

The authors examined interventions aimed at encouraging early language stimulation in babies with Down syndrome in Spain. The sample comprised 35 babies in three age groups: Ago (between newly-borns and first month), Ag3 (between three and four months) and Ag6 (between six and seven months). With the facts obtained in diagnosis, observation and the social interview, an individualised language stimulation programme was drawn up.

The results showed that early intervention improved the Language Development Quotient (DQ) of all the groups under study; however the best scores were achieved by those children who started the treatment soon after being born. It was therefore concluded that a three month delay in the beginning of treatment could cause an observable Language DQ decrease at eighteen months of life.

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Stoel-Gammon highlights a number of factors that influence a child with Down syndrome’s phonological system and accordingly, their ability to perceive and produce speech. For example:

- children with Down syndrome often also suffer from mild to moderate hearing loss. This will further compromise the language learning environment;
- differences in anatomy and physiology; and
- the language learning environment and the nature of the linguistic input they receive. This highlights the importance of social interaction, in particular, with caregivers, in language acquisition.

Evidence shows that pre-linguistic vocal development in children with Down syndrome is the same as normal peers, however language development is not. There can be issues in transitioning to productive speech. There is also a risk that speech can remain unintelligible. Stoel-Gammon notes that there are specific early intervention strategies targeted at many of these problems.

Burgoyne describes the developmental foundations and potential benefits of reading interventions for children with Down syndrome. It is noted that many children with Down syndrome are now attending mainstream schooling and accessing the same level of literacy teaching as their peers. Research suggests that children with Down syndrome aged between seven and fourteen typically achieve a reading age of between five years five months and ten years. However, there is wide variability in the level of skills achieved. Some can even achieve skills in advance of their chronological age.

It is therefore important to provide support to allow them to reach their full potential. Reading is important for speech, language and memory skills. Children need to develop skills in word recognition and language comprehension.

Development of phonological awareness skills may also play an important role. A number of researchers have investigated the efficacy of training focussed on this area, noting that parents may also be able to deliver the training. Studies have shown promising outcomes.

Burgoyne argues that reading instruction, and specifically, phonological awareness training, can be effective in supporting the development of reading in children with

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Down syndrome. There is still wide variation in outcomes, including where the interventions are provided to typically developing children. For example, other evidence suggests that it may need to be combined with vocabulary training. This may be beneficial given language impairments are common in children with Down syndrome and evidence suggests that oral language skills can play a key role in developing their reading skills.

The other key component is reading comprehension. While evidence is limited, what is available suggests that reading comprehension is typically below reading accuracy for children with Down syndrome. This can be impacted by difficulties with language and memory. Work with typically developing children suggests that teaching comprehension strategies can be effective. While not designed as an early intervention, Burgoyne cites a study of six young adults with Down syndrome where this was effective.

Visual imagery training may also be beneficial for children with Down syndrome as there is evidence to suggest that they particularly benefit from visual learning. However, more evidence on this is needed, particularly using well designed controlled methodologies.

Snowling, Nash and Henderson examine the development of literacy skills in children with Down syndrome and the implications for early intervention. They comment that the relatively recent policy of educating children with Down syndrome in mainstream schools is showing positive outcomes in terms of language skills and academic achievement. Children with Down syndrome in mainstream schools are outperforming their peers in special schools in reading and language.

The home environment is also important. Anecdotal evidence demonstrates benefits of reading in the pre-school years. Reading skills can be an area of strength in children with Down syndrome. Most acquire literacy although outcomes vary, depending on factors such as cognitive ability, expressive and receptive language skills and phonological awareness. Comprehension skills is also an important issue.

The authors report literacy interventions in children with Down syndrome, including:

- phonological awareness training: Kennedy and Flynn (2003) – found that phonological awareness improved but did not positively impact speech production;

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• phonological awareness training: Van Bysterveldt, Gillon and Moran (2006) – a program based on training parents showed improvements in phonological awareness and letter knowledge; and

• reading intervention – reviewed studies of a number of different techniques. It was concluded that much more research is required, however evidence to date may suggest that word recognition skills are more amenable to training than phonological awareness skills or decoding abilities.

Evidence also suggests that variance in ability results from genetic and environmental differences. Studies therefore need to map relations between cognitive abilities, language and reading skills.

An Australia study by Cologon examined early intervention strategies in reading for children with Down syndrome.260 A total of 15 children participated in the study, in which two interventions were compared: a Phonological Awareness (PA) intervention and Silent-Reading (SR) intervention. Participants were assigned to interventions based on a range of scores including initial assessments of general ability, phonological awareness and reading ability.

The PA intervention facilitated greater development of phonological awareness and phonic decoding skills, while the SR intervention facilitated greater improvements in reading comprehension. The study showed that with early intervention, children with Down syndrome can develop the sub-skills required for skilled reading, which contradict the claims that reading ability develops in the absence of phonological awareness or reading comprehension in children with Down syndrome.

Light and Drager examined the effects of an Augmentative and Alternative Communication (AAC) program for children with Down syndrome.261 They noted that children with Down syndrome can experience significant delays in speech development, which can negatively impact other areas. Children with Down syndrome have limited means of expression in early years, and limited communication means that it can be difficult to assess their abilities. This highlights the importance of early intervention.

The AAC program uses strategies and techniques to enhance communication when speech is inadequate or children are at risk of delay. It includes unaided systems (e.g.


gestures) and aided systems (communication boards or books). This is used to maximise speech development, not to substitute for it.

This study evaluated the effects of an AAC intervention on speech, language and communication development in a group of young children with Down syndrome that had no functional speech at the start. The sample included six children with Down syndrome aged between six and sixteen months at start of study (21 to 37 months at end of data collection). Intervention was scheduled for one hour per week, doing activities such as social games, singing songs, book reading and play activities.

The children improved from limited means of communication to multiple means. There was significant growth in their expression of concepts, with children able to combine concepts to express more complex meanings. They therefore concluded that AAC intervention offers a means to stimulate language and communication development with young children with Down syndrome.

Light and Drager observe that effective early intervention requires the application of both science and art. The science involves the implementation of evidence-based procedures, that are monitored for effectiveness and outcomes are evaluated. In terms of art, this involves “the belief and the commitment to the right of all individuals to express themselves fully and seek their full potential.”

Jeyes and Newton observe that it is well known that children with Down syndrome have difficulties with auditory processing and language development. Their paper documented a pilot study of the Listening Program as a prelude to a more formal study. Under this program children listen to acoustically modified music through headphones. It is designed to stimulate and exercise different functions of the auditory processing system and better process, store and use auditory information. The Listening Program has been designed by a multidisciplinary team, building on the work of Tamatis - an ear, nose and throat surgeon.

The study involved nine children between the ages of five and twelve years who participated in the Listening Program. They used the Listening Program over a ten week period for two 15 minute sessions, five days per week. Outcomes were measured using a range of tests.

The results showed clearer speech, more extensive vocabulary, and the use of a greater number of words which are more effectively sequenced. Participants also showed a


greater attention span from improved auditory discrimination and improved communication with their peers and the school staff. These findings provide positive support for the Listening Program.

A.3 Numerical skills

As highlighted by Rouse, much of the research in learning for children with Down syndrome has focussed on language skill. Very limited attention has been given to numerical and mathematical abilities, which are an important part of daily life. Overall, children with Down syndrome can vary widely in their achievements and interest in maths.

For children with Down syndrome, numerical skills tend to be behind literacy skills and are often reported as a concern by teachers. Children with Down syndrome can be weak in using memory skills and problem solving strategies but tend to be strong visual and tactile learners. Activities that focus on these skills can be beneficial when teaching numbers and mathematical skills to these children.

This study evaluated whether the multi-sensory approach of Numicon was effective in teaching number skills to children with Down syndrome in elementary school. Three elementary level children (aged eight to eleven years) participated in the study. It involved 30 minute sessions of individual math instruction over a period of 20 days using the Numicon approach.

Following the program, students were able to correctly count numbers, understand the addition process and were beginning to develop their own mental imagery of numbers and mentally calculate more single digit addition problems. The multi-sensory math teaching approach of the Numicon Foundation kit was found to be an effective instructional program for teaching patterning, ordering, counting, place value, simple addition, and simple subtraction.

While we have otherwise sought to limit our focus to strategies targeted at infants and young children, this study provides an example of using one of the strengths of children with Down syndrome to improve a potential weakness. This could have implications for other early intervention strategies.

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A.4 Motor skills

Aparicio and Balana examined a fine motor intervention in children with Down syndrome in Spain.265 Specific deficits in children with Down syndrome can adversely impact fine motor skill levels. This can be exacerbated by environmental factors, in particular, difficulties experienced by parents in visually interacting with their children, detecting their needs, attracting their attention and working with them. Indeed, studies have shown that the family environment for children with Down syndrome is different than the environment for children without Down syndrome, providing less chance for fine motor interaction.

Intervention can help families understand the problem and more effectively work with their child, which can benefit fine motor intervention. This study examined an early intervention targeted at fine motor skills for children.

A sample of 30 children with Down syndrome was used to study at different ages: Age-6 (from four to six months) and Age-9 (from eight to nine months until 18 months of age). Each subject included in the experiment underwent a diagnostic examination and an observation period. An individualised stimulation programme was then drawn up. Parents were also involved in the treatment.

The outcomes showed that early intervention improved the performance of both groups compared to preliminary diagnosis. The best scores, however, were achieved by those children who started the treatment by six months of age. It was concluded that the levels of development exhibited by children could be considerably improved if the treatment is started as soon as the disturbance is detected.

While massage therapy is not typically prescribed for children with motor problems, research findings suggest it may enhance development for children with Down syndrome. One possible explanation is that providing for the experience of normal movement might increase the attainment of milestone skills. Massage therapy is a passive treatment posing little if any physical demands.

Hernandez-Reif et al sought to test whether massage therapy improved muscle tone in children with Down syndrome.266 It also sought to test whether this would then facilitate motor development, and then, would enhancing muscle tone and motor development enhance development in other areas.


The study group comprised 22 moderate to high functioning young children with a mean age of two years. They were assigned to additionally receive two thirty minute massage therapy (study group) or reading sessions (control group) per week for two months.

The results showed that all children showed developmental gains in all areas. However, children in the massage therapy group showed greater fine motor and gross motor functioning than the control group. They also generally found improved scores in many areas, including cognition and social development, for both groups.

The authors concluded that when added to an early intervention program, massage therapy may enhance motor functioning and limb muscle tone for young children with Down syndrome. They did recognise that some of the changes could be attributable to maturation effects. This would have been addressed by the control group receiving no early intervention.

Mahoney, Robinson and Fewell examined the effects of early motor interventions for children with Down syndrome and Cerebral Palsy. Motor interventions can be perceived as homogeneous and that ‘more is better’. However, there is considerable heterogeneity as to the models applied, the frequency of use and the discipline applied by practitioners. Limited research has been done on interventions specifically targeted at motor outcomes.

Two common types of motor development problems are observed: overall motor delay (usually observed in Down syndrome) and impairment in the formal and development of control over movement patterns required for typical motor functioning (more common in Cerebral Palsy). Each requires different intervention models.

This study investigated two models of motor intervention implemented for children with Down syndrome and Cerebral Palsy, being NDT (neurodevelopmental treatment) and DevS (developmental skills). The sample included 50 children. The analysis was not conducted in highly controlled conditions but instead aimed to determine what was happening in actual, diverse intervention settings.

The results were disappointing. Children did not show a rate of motor growth during intervention that exceeded what could be attributed to maturation. They did find a small but significant effect in relation to amount of services received and the effect of intervention. The study found no evidence that training of the practitioners influenced outcomes.

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The authors observed that these results may mean that neurodevelopmental treatment approaches are flawed and that focus needs to be on functional skill development. In saying that, caution needs to be exercised in assuming that functional skill training will enhance the effectiveness of motor interventions. Effective models may need to incorporate instruction of parents and caregivers to provide continuity of experience. It should also be noted that the study design was not based on a randomised controlled trial.

Dominant early intervention services for motor functioning have not proven to be effective. Mahoney and Perales propose two main reasons for this:\textsuperscript{268}

- parents are not being involved as active participants in the intervention; and
- contemporary models of motor intervention have been focussing on activities that are incompatible with current theory and research

They observed intervention activities and reviewed logs, and found that parents had very limited involvement in interventions:\textsuperscript{269}

...given the low level of effort that went into to parent involvement in our study, it is not surprising that intervention had no effect on parent-child interaction or that parent participation did not affect intervention outcomes.

Mahoney & Perales also compared the effectiveness of NDT and DevS (see study above). The approaches are very different in terms of the behaviours that are the focus of the intervention sessions. Importantly, these behaviours are not the ones identified in contemporary research as being the most important influencers of motor development. For example, Dynamic Motor Theory states that motor development is a consequence of children constructing solutions to motor problems. Child-initiated motor activity is therefore very important. Interventions may need to be targeted at encouraging this.

The study concluded that it is difficult to maximise a child’s level of motor activity without parental involvement. For example, based on the authors’ own analysis of time spent by professionals in interventions, parents have the opportunity to have at least 200,000 more interactions with the child in a year. It is recognised that further work is needed as to whether parents will have the skills to do this. For example, one practice that has been investigated is spontaneous stepping practice on treadmills, which can be

\textsuperscript{269} Mahoney & Perales (2006), p 69.
implemented by parents. The other key dimension is parents’ responsiveness in child interactions. Overall, it was observed that further research is needed in this area.

A study by Torres and Buceta examined intervention for motor development, specifically, an early intervention program in Spain based on the Portage Guide, adapted to the specific needs of each child. Programs involve work in various development areas, with psychomotor development being one of the key goals. The study focused on the impact of parental involvement on outcomes.

The sample comprised 24 infants aged zero to two years who attended the early intervention unit at a hospital. Children attended the unit for an hour at a time, three times per week. Parents were instructed to continue with the program at home on a daily basis.

The results showed that good parental involvement ensured maintenance of a more or less constant development quotient (DQ), while poor parental involvement was associated with a very marked decline in DQ.

It was therefore concluded that active parental involvement has a positive effect on the development of infants with Down syndrome. Poor parental involvement can have a particularly negative effect on motor development in infants whose initial deficit is relatively minor. These results clearly demonstrate the importance of active parental involvement in early intervention programs, at least as regards motor development between birth and age two years.

Ulrich et al examine the effectiveness of treadmill training in children with Down syndrome. On average, infants with Down syndrome may not begin walking until one year later than infants that do not have a disability. Walking has multidimensional impacts. It can influence cognitive, social and motor development and affects a child’s ability to interact with peers.

Parents of infants with Down syndrome have also identified walking as a highly valued goal. Failure of the child to walk can increase stress and reduce parents’ satisfaction with life.

It has been observed that the stepping reflex observed in newborn infants when held upright can provide a key as to how to teach infants to walk. Eliciting this reflex has been shown to result in walking. It has been found that this could be induced in infants

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with disabilities using a small motorised treadmill, noting that this is something that parents can administer in the home. It was noted that other research has shown that practicing movement patterns can improve and integrate functional motor responses. Treadmill training is based on this principle by significantly increasing the practice of a walking movement.

This study examined a group of children with Down syndrome in the US. Thirty families of infants with Down syndrome were assigned to an intervention or control group. Infants in the intervention group received practice stepping on a small, motorised treadmill, five days per week for eight minutes per day, in their own home with parents’ support. The intervention group learned to walk with help and to walk independently significantly faster than the control group.

It was concluded that with training and support, parents can use their treadmills in their homes to help their infants with Down syndrome learn to walk earlier than they normally would. This evidence raises a number of other questions for future research, such as the impact of improving independent movement on overall development.

Virji-Babul et al examined perceptual-motor interventions for children with Down syndrome and the implications for intervention.\textsuperscript{272} Motor impairments are common in children with Down syndrome. It remains unclear whether motor-based intervention programs impact on long term developmental outcomes in motor functioning in people with Down syndrome. One reason for the limited success may be that interventions have been influenced by traditional approaches that have been based on the developmental trajectory of normal-functioning children.

Motor system does not function in isolation. Motor processes interact with perceptual processes. There is some evidence in the literature to suggest that children with Down syndrome have impairments in perceptual-motor coupling (e.g. observation of children having difficulties in adjusting actions when they encounter obstacles of two different heights).

An approach that has been applied to test perceptual-motor coupling elsewhere is a visual analysis of point-light displays of human and object motions. This study applied this to children with Down syndrome, examining a group of children aged from eight to fifteen years.

This technique can be used to determine if children can make basic perceptual discriminations between human and object motions. The study also examined their

ability to process more complex environmental stimuli and determine if children with and without Down syndrome differ in their abilities to perceptually discriminate between complex motoric stimuli.

The results revealed that children with Down syndrome can make basic perceptual discriminations between human and object motions, although children without Down syndrome displayed superior performance. It was also evident that the children with Down syndrome are impaired in their perception of emotion from static facial expressions, and had difficulties in perceptually discriminating between complex motoric stimuli.

The authors identified a number of implications for early intervention. ‘Bottom up’ early intervention approaches are not necessarily successful (that is, isolating and treating specific motor components). Instead, therapists need to focus on enhancing early perceptual-motor competencies in infants with Down syndrome. These interventions could facilitate the development of interpersonal skills and social competence. Perceptual-motor skills are taught within the context of play. Interventions still target specific domains but within the broader context of social competence.

A.5 Parental involvement

Mahony and Perales describe how the early learning sequence for children with Down syndrome is the same as for other children; however it typically occurs at a slower rate. The key reasons for this are compromised neurological processes that result in less efficient learning and the presence of ‘pivotal behaviour deficits’ that limit engagement in repetitive play and social activities that are the foundations for developmental learning.

They discuss Relationship Focussed Intervention (RFI), which is:

...an approach to promoting the developmental and social emotional functioning of young children with developmental delays by encouraging parents to engage in highly responsive interactions with them.

There is increasing evidence that shows the effectiveness of RFI in accelerating development in children with developmental delays, including Down syndrome (the authors point to more than 20 published studies). However, it is still viewed as


controversial because it differs from other strategies that are more commonly used in early intervention practice, that is, those that are more behaviourally focussed. RFI encourages carers to respond to and support their child’s existing communications and actions.

This paper addresses the conceptual issues with RFI, based on observations of three children with Down syndrome when they were playing by themselves. The most salient characteristic was the extent to which they practice or repeat certain developmental behaviours that characterise their current stage of development and propose that: \(^{275}\)

RFI enhances children’s development less by teaching the skills and behaviours that characterise higher levels of developmental functioning and more by encouraging assimilative learning processes of practice and repetition.

RFI does not involve parents teaching developmental skills. Instead, it teaches strategies to interact with the child, for example, supporting previous behaviours and promoting parent child reciprocity. The strategies mainly impact the child’s participation and engagement in interactions. This in turn can encourage children to develop the habit of using pivotal developmental behaviours.

Mahony and Perales showed that in a recent evaluation of RFI, the degree to which strategies successfully encouraged parents to increase their responsiveness with their children was directly related to an increased use of pivotal behaviours by the child. They also consider that after a few months of RFI, children are more likely to be able to learn advanced developmental behaviours that are used in other intervention strategies. That is, it helps the child learn more efficiently through repetition and assimilation.

Giudice et al note that with the benefits of early intervention widely acknowledged, focus has now shifted to the whole family, in particular, the importance of parental involvement. \(^{276}\) In Italy, services for children with developmental delays still lacks specific intervention programs implemented on a regional or national basis. The focus has been on services implemented by professional therapists; however the concept of teaching parents specific skills has not been supported. There are also marked regional differences in income level and unemployment rates, as well as the quality of health care services.


This study compared the efficacy of a standard program administered by therapists offered by the Italian NHS and a parent-implemented developmental training program. A total of 47 children with Down syndrome were randomly assigned either to the experimental group (intervention implemented by parent) or to the comparison group (intervention implemented by a therapist). It was a 12 month intervention program, completed by 32 children.

After a 12 month follow-up, children in the experimental group showed developmental gains over time while children in the comparison group showed a slight but not statistically significant improvement. Overall, the results did not enable the conclusion that parent-implemented therapy was more effective than therapist-implemented treatment, noting that the content of the program, and a number of other factors, varied between the two. However, it supported the conclusion that a parent-implemented approach would appear feasible.

Iaroocci, Virji-Babul and Reebye reviewed the Learn at Play Program (LAPP) which is advocated as a social competence model for children with Down syndrome. They observe:

The chromosomal anomaly in DS has powerful and specific influences on development, the consequences of which may be considered so great by adulthood that environmental interventions have relatively little to contribute. Conversely, in the early stages of development, the prognosis of infants and young children with DS is more promising, as recent evidence in the neurobehavioral sciences indicates that brain development is quite malleable and responsive to early pre-, peri-, and postnatal influences.

The effects of Down syndrome extend to the potential disruption of the family system and the relationships between and functioning of family members. When a child with Down syndrome enters the family a significant readjustment is required. This can be more difficult given the demands placed on the primary caregiver. The mother and infant subsystem can also be at risk. Negative attitudes from health professionals about future expectations and success can exacerbate stressors.

Disability can have a negative impact on parental confidence and satisfaction:


Alternatively, parents may thrive in their unique roles as their child’s advocate, case manager, and teacher but at a significant cost to their roles as play partner, emotion regulator, and nurturer of self-identity and autonomy. The functioning of the family system and its various subsystems need to be considered as the “special needs” extend beyond the child with DS.

Designing early intervention programs therefore needs to “integrate the child and family processes within a dynamic transactional model”\textsuperscript{280}. That is:\textsuperscript{281}

\begin{quote}
The emphasis of an early intervention program is to foster, facilitate, and optimize interactions between children with DS and their carers and other social partners and, thus, build social, affective, and cognitive development in the child as well as family wellness.
\end{quote}

These authors advocate a developmental systems perspective to improve understanding of parent-child interactions and their influence on the child’s development, as well as the interplay of the various social support systems available.

The LAPP is advocated as a social competence model of early intervention for children with Down syndrome, with social competence having been identified as an overarching goal of early intervention. This recognises that development is dynamic and integrated. Accordingly, more of a ‘top down’ approach is required. Social competence leads to improvements in basic foundational skills and more complex interpersonal skills.

The main goal of LAPP is to optimise and support the development of social competence in children with Down syndrome, as well as family well-being. The key medium used is play. Tasks are modified as the child develops, with intervention targeting specific domains that are affected by Down syndrome within the broader framework of social competence.

The study examined seven children with Down syndrome and their parents who participated in the LAPP program, based on one intervention session per week for eight weeks over two years. Variability in performance on cognitive and adaptive measures were reported. Observed variability in the quality of interactions between parent and child could suggest that explicit interventions regarding the goals and quality of interactions may be necessary for certain dyads.

Mahoney et al examined a program called Responsive Teaching. This is an early intervention curriculum designed for implementation by parents and caregivers, the aim of which is to maximise the potential of routine interactions in order to support development. It involves encouraging children to develop and use ‘pivotal behaviours’ that are targeted at promoting three key domains of development, being cognitive, communication and social-emotional functioning.

Responsive interactions do not teach new skills. They reinforce existing skills and knowledge. The idea is that active engagement in activities promotes learning.

In examining the effectiveness of Responsive Teaching the authors refer to a study by Mahoney and Perales (2005). This study reported results of a one year evaluation of 50 mother-child pairs. The children were aged 12 to 54 months. Twenty children had ASDs and 30 had developmental disorders (only one child had Down syndrome). There was no control group.

The results of this study were that mothers significantly increased their levels of Responsiveness and Affect when interacting with children as a consequence of the program. Children also made improvements in all seven areas of the Child Behaviour Rating Scale (CBRS). The rate of change of development during intervention was 123% greater than before intervention, with a 64% increase in the rate of cognitive development, a 167% increase in rate of expressive language development and 138% increase in receptive language development. They also found a relationship between change in mother’s responsiveness and their children’s behaviours. Overall, they found that children made “remarkable developmental and social emotional improvements when their parents used Responsive Teaching with them.”

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B Autism

Synergies previously undertook a review of the literature on the benefits of early intervention for children with autism in 2006. The following summarises this review in addition to the review of studies from 2007 onwards that were assessed for the purpose of this report.

The majority of the literature on the outcomes from early intervention for children with autism prior to 2006 focused on behavioural intervention. One of the most high profile studies undertaken in this area was by Lovaas, who noted the positives and negatives of behavioural intervention:

On the positive side, behavioural treatment can build complex behaviours, such as language, and can help to suppress pathological behaviours, such as aggression and self-stimulatory behaviour...On the negative side, treatment gains have been specific to the particular environment in which the client was treated, substantial relapse has been observed as follow-up, and no client has been reported as recovered.

Participants in this program were assigned to one of two groups: an intensive treatment group consisting of 19 children receiving more than 40 hours of one-on-one treatment per week, and a minimal treatment control group (also consisting of 19 children) receiving 10 hours or less of one-on-one treatment. Both groups received treatment for at least 2 years. Children were not randomly assigned to groups due to ethical considerations.

The initial clinical assessment describes the children as an average (or below average) sample of autistic children. The two groups were seen as reasonably comparable at intake. Lovaas’ assessment of the outcomes of this study revealed that the experimental group increased their IQ by an average of 30 points over the control group. The number of children achieving within the normal range of functioning increased from two to twelve, with the number of children in the moderate-to-severe range of mental retardation dropping from ten to three. 47% of the group achieved normal intellectual and educational functioning, meaning successfully passing ‘normal’ first grade and achieving an average IQ, compared to 2% of the control group.

Lovaas concludes his paper by highlighting the need for longer-term follow-up studies:

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But questions can be asked about whether these children truly recovered from autism...certain residual deficits may remain in the normal functioning group that cannot be detected by teachers and parents and can only be isolated on closer psychological assessment, particularly as these children grow older.

Two follow-up studies have been done involving the same group of children. The first, by McEachin, Smith and Lovaas, examined the progress of the children at age twelve, and found that of the nine children that achieved the best outcomes in the original study, eight continued to function normally. The second, by Smith, Wynn and Lovaas, followed up the same children as young adults and showed that the gains continued without further intervention.

There have been several criticisms of Lovaas’s study. These criticisms include the fact that the outcomes had not been able to be successfully replicated. Further, the use of aversives as part of the reinforcement controls were subsequently removed from the Lovaas methodology and no studies had been conducted to determine the extent to which this change might impact the outcomes achieved. A lack of random assignment to the experimental and control groups has been another key criticism in addition to the fact that the sample population was not representative of children with autism.

Sallows and Graupner document Lovaas’ multi-site autism project, which sought to address these concerns. This project involved the use of several sites and the random assignment of children to the intensive treatment group, involving 40 hours of treatment, and a parent-directed group, where less intensive behavioural treatment was delivered (it eventuated that on average, 29 hours of treatment per week was provided in this group). The parent-directed group involved the parents determining the intensity of treatment delivered, as well as whether other treatments might also be used. For the intensive treatment group, treatment fidelity was addressed by ensuring all staff satisfied quality control criteria established by Lovaas. Aversives were not used as part of the treatment program.

The results documented by Sallows and Graupner showed that across both groups, average IQ increased by 22 points (compared to 21 point increase in Lovaas’ original study) with 33% achieving an IQ of 90 or higher. The average IQ in the parent-directed

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289 Aversives are unpleasant stimuli that induce changes in behaviour through punishment.

group was four points higher. On other measures, the intensive group achieved higher outcomes. Overall, the average gain in language was thirteen months in comprehension and eight months in expressive skills.291

The authors conclude that this study demonstrates that the treatment could be replicated in a clinical setting outside a university, and that Lovaas’ earlier findings could be replicated without aversives. The unexpected outcome was the very positive results that were also achieved in the parent-directed group, which they suggest is attributable to the greater level of parent involvement.292

Overall, therefore, while the study did provide some support for the potential effectiveness of the Lovaas method, implemented outside the original setting, similar positive outcomes were achieved for reasonably intensive parent-directed behavioural intervention, which did not involve strict adherence to the Lovaas methodology.

Boyd and Corley, noting the “widespread proliferation” of Lovaas-based programs that has occurred, undertook a survey in one of 21 non-profit agencies in California that has been providing these services.293 The services are based on providing two years of 30 to 40 hours per week of discrete trial training in the home, with possibility of a further 10 hours if the child had demonstrated reasonable progress. There were 22 participants in total, 19 of whom were diagnosed with autism and 3 with PDD-NOS. The average length of treatment was 23 months (ranging from 9 to 36 months). Outcome measures were based on those utilised by Lovaas.

The limitations identified with the methodology used for this study were that the sample size was relatively small, there was no control group, and it did not formally assess the extent to which participants would have benefited from the intervention even if the targeted measures of ‘recovery’ were achieved.

In this study, no child was seen as having achieved ‘recovery’ based on Lovaas’ criteria. No child had normal intelligence or had been placed in regular education without a 1:1 aide and 68% were considered mentally retarded. Eight children met the threshold Frankland factor for very serious behavioural problems and two others were close to this threshold. Developmental areas showing the most improvement included language (63%), compliance (31%) and pre-academic skills (31%). Areas showing the least improvement were pragmatic language (50%) and socialisation (31%). More than 50% were described by their parents as being “largely non-verbal”.

In terms of parental satisfaction, 44% of respondents indicated that they were very satisfied with the implementation of the program and 25% were satisfied; while 69% were also either very satisfied or satisfied with the outcomes of the program, although only 25% were very satisfied. 15 out of 16 indicated that they would recommend the program to other parents.

The findings from this study temper the positive claims about recovery rates from community-based EIBI treatment programs. It also highlights the difficulties in replicating the treatment integrity. The findings also question the justification for such intensive treatment. The authors suggest that future research would be needed to determine whether this yields benefits in later life.294

As is stated above, Lovaas’ study has been subject to significant criticism, based predominantly on concerns regarding the implications of the claims of the potential for participants to achieve ‘normal’ functioning. These criticisms led to a study being commissioned to assess the extent to which the claims regarding the potential benefits of the Lovaas treatment could be validated.295 The studies that were examined are summarised in the following table.

<table>
<thead>
<tr>
<th>Report</th>
<th>Design</th>
<th>Subjects</th>
<th>Intervention</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lovaas 1987 (McEachin et al 1993)</td>
<td>Prospective: 3 to 7 yrs Assigned based on location/therapists</td>
<td>Experimental: n =19 Control 1: n=19 Control 2: n=19 Age: less than 40 to 46 months</td>
<td>Min 40 hrs Lovaas therapy</td>
<td>Blinded Experimental: 9/19 normal functioning Control: 0/19 normal functioning</td>
</tr>
<tr>
<td>Birnbauer and Leach (1993)</td>
<td>Prospective: 2 yrs Matched control</td>
<td>Experimental: n=19 Control: n=5 Mean age 39 months</td>
<td>Mean 29 hrs Lovaas therapy</td>
<td>Not blinded Experimental: no normal functioning 4/9 achieved IQ &gt;= 89</td>
</tr>
<tr>
<td>Sheinkopf &amp; Siegel (1998)</td>
<td>Retrospective: 21 months Matched control</td>
<td>Experimental: n=11 Control: n=11 Mean age 33 months</td>
<td>Mean 27 hrs Lovaas therapy</td>
<td>Intake blinded Experimental: no normal functioning Mean IQ 25 pts higher</td>
</tr>
<tr>
<td>Ozonoff &amp; Cathcart (1998)</td>
<td>Prospective: 10-12 wks Assigned first 11 children to experimental; next 11 to control</td>
<td>Experimental: n=11 Control: n=11 Mean age:33 months</td>
<td>10 home sessions TEACCH therapy</td>
<td>Not blinded Experimental: no normal functioning Experimental: improved 9 months on developmental scale</td>
</tr>
</tbody>
</table>


This review highlighted concerns with the external validity of the Lovaas approach, including that it would appear to be restricted to higher-functioning children with autism. It concludes that there is insufficient evidence to establish a causal relationship between this form of behavioural treatment and ‘normal functioning’, notwithstanding that there are clear benefits from some form of early intervention therapy.\(^{296}\)

Further, the benefits have not been substantiated by other independent studies. They note that hope regarding the possibility for normal functioning to be achieved has become a “rallying point” for services planning, when instead it should become a basis for future research.\(^{297}\)

A study by Strain and Hoyson outlined the preliminary results for six children involved in the LEAP program.\(^{298}\) These were the first participants to complete the research protocol, with another 45 enrolled. The key features of the program included individualised objectives and strategies, focus on the ability of children to generalise skills across multiple contexts, maximisation of instructional opportunities, and a focus on family skills.

One of the measures used to assess outcomes was the childhood autism rating scale (CARS). Children commenced intervention with scores placing them in the moderate to severe range. At exit and age ten, their behavioural symptoms reduced to the point where on the CARS scale, they would no longer be classified as autistic.

In terms of developmental functioning, the authors noted that gains can be difficult to determine based on the different assessment tools used, however it would appear that substantial gains were made in this area. Significant improvements in child-appropriate behaviour were seen over the two years and maintained through age ten, mostly via sharp reductions in non-compliance. Direct observation of social interactions noted substantial behavioural improvements, with the mean level of positive interaction increased from 3% at entry to 23% at exit. After leaving LEAP, five of the six children were in regular schooling without special education.\(^{299}\)

A study by Mesibov noted a number of studies that had demonstrated beneficial outcomes for the TEACCH program.\(^{300}\) TEACCH is described as a structured program

\(^{296}\) Bassett, Green & Kazanjian (2000).

\(^{297}\) Bassett, Green & Kazanjian (2000).


\(^{299}\) Strain & Hoyson (2000).

that aims to assist people with autism of all ages and level of functioning. While there are similarities between TEACCH and behavioural approaches given the emphasis on structured learning. A number of studies have shown beneficial outcomes for participants in TEACCH programs including:

- improvements in attending, relatedness, affect and general behaviour (Schopler et al, 1971);
- an increase in appropriate behaviours, particularly in play or work and communication, as well as improved social interaction. These improvements were generalised to settings outside the clinic situation (Short, 1984); and
- improvement on imitation, fine motor skills, gross motor skills and non-verbal conceptual skills (Ozonoff and Cathcart).

Mesibov also cites examples of programs deriving high levels of satisfaction for both parents and professionals.  

Salt et al evaluated a Scottish early intervention programme with a social-developmental therapeutic approach. It compared two groups of pre-school children with autism. The two key aims of the study were to examine the outcomes for the children, as well as determine whether it had reduced parental stress.

This study is a controlled treatment outcome study, involving fourteen children and their parents in the experimental group and six in the waiting list control group. Standardised assessment tools were used, including: Bayley Scales of Infant Development, British Picture Vocabulary Scale; Vineland Adaptive Behaviour Scales; Pre-verbal Communication Schedule; MacArthur Communication Development Inventories; Symbolic Play Test; Early Social Communication Scales and Parenting Stress Index.

Overall, the treatment group showed significantly more improvement than the control group in the following areas: socialisation; daily living skills; motor skills; adaptive behaviour; imitation; joint attention; and social interaction. Improvements in the treatment group were notable given that children in the control group had a

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301 For example, in a study in Northern Ireland, over 86% of parents and professionals described TEACCH as effective, citing examples of improvements in self-help skills and social skills, and a reduction in inappropriate behaviours. Also, the Swedish National Autism Society sponsored a five year study of TEACCH programs in Sweden which found that virtually all of the parents and professionals found the training to be useful and satisfying, with 70% describing it as excellent in helping them work with autism even four years after their participation.


significantly higher mean IQ at the start. Both groups improved on the MacArthur Communication Development Inventories and Symbolic Play test. There were no significant reductions in parental stress observed for either group.\textsuperscript{304}

Overall, the authors claim that this study provides an example of an effective social-developmental treatment approach that is more “naturalistic” rather than discrete trial based. Using only eight hours of treatment per fortnight, it is therefore significantly less intense than other approaches and potentially questions conclusions regarding the positive correlation between intensity and outcomes. The limitations of the study were that assignment between groups was not random; the sample size was relatively small; and it focussed on immediate outcomes. A longer-term follow-up study is therefore needed.

A study by Remington et al\textsuperscript{305} assessed the outcomes of 23 preschool children with autism who were placed in an early intensive behaviour intervention program and compared the results to the outcomes of 21 children with autism receiving treatment as usual. The children were aged between 30 and 42 months at the time of program induction, with assessments being undertaken prior to the commencement of treatment, after one year, and after two years. The study also assessed the impact of the respective programs on parental stress and interactions between the children and their parents.

The two year assessment showed significant differences between the two groups in terms of intelligence, language skills, daily living skills, and positive social behaviour. The effect size for the impact of the intensive intervention program was substantial and clinically significant at the group level, with the impact almost exclusively confined to children’s cognitive and language abilities and adaptive functioning capabilities.

Using the reliable change index statistic developed by Jacobson and Truax (1991), the study found that 26\% of the children in the intensive intervention group achieved a positive IQ change that was statistically reliable in addition to none showing a reliable regression in IQ levels. However, in the comparison or treatment as usual group, while 14\% of children improved reliably, a further 14\% also regressed reliably in terms of their IQ levels. There was no evidence that the intensive intervention program created additional problems for parents of children with autism.

\textsuperscript{304} Salt et al (2002).

While the study provides support for the positive outcomes that can be achieved for children with autism under early intervention programs, the following limitations need to be acknowledged:

- the study was not a randomised control trial, meaning that pre-existing differences in the two groups could potentially have impacted on the results; and
- the sample sizes used in the study were relatively small, limiting the extent to which credible conclusions can be drawn from the study results.

Keen et al[^306] investigated the effects of the Stronger Families Project on the communication and symbolic abilities of young children with autism. The Stronger Families Project is a social pragmatic intervention. The study population consisted of 16 children with autism aged between two and four years.

Results from the study were based on reports from parents, caregivers and independent observers. While parent reports indicated changes in some communication and symbolic behaviours as a result of the intervention, improvements recorded based on the reports of independent observers were not significant. Reasons for this may include:

- significant variability between independent observers’ ratings of the same children’s behaviour;
- the small sample size; or
- parent and caregiver bias.

In addition to its small sample size, the study is also limited by the lack of a control group for comparative purposes and also its reliance on subjective ratings from parents, caregivers and independent observers.

Eikeseth et al conducted a study assessing the outcomes for children with autism who had received intensive behavioural treatment, commencing between the ages four and seven.[^307] The purpose of this study was to extend the findings made by Eikeseth et al (2002) on the positive effects of intensive applied behaviour analytic treatment for children with autism who began intervention at a mean age of five and a half years. The study compared the outcomes of a group of 13 children in a behavioural treatment group with the outcomes of a group of 12 children assigned to an eclectic treatment group.


An evaluation undertaken at a mean age of eight years and two months indicated that the behavioural treatment group showed significant increases in IQ levels and adaptive functioning abilities relative to the children in the eclectic group. Children in the behavioural treatment group also displayed fewer aberrant behaviours and social problems relative to the eclectic treatment group.

The outcomes for adaptive behaviour, communication, daily living skills and socialisation were measured using the Vineland Adaptive Behaviour Scales. These scales are a commonly used test to assess levels of adaptive functioning in children and adults.

The main results observed in the study for both of the study groups were as follows:

- in terms of IQ levels, the behavioural treatment group gained an average of 25 points compared to 7 points for the eclectic treatment group;
- the behavioural treatment group gained an average of 12 points in adaptive functioning, compared to an average reduction of 10 points for the eclectic treatment group;
- the behavioural treatment group recorded an average increase of 20 Vineland points in relation to communication skills, compared to an average reduction of 7 points for the eclectic treatment group;
- in relation to daily living skills, the average increase recorded by the behavioural treatment group was 9 points which contrasted to the average reduction of 6 points recorded by the eclectic treatment group; and
- the behavioural treatment group gain an average of 12 Vineland points for socialisation, compared to a reduction of 12 points for the eclectic treatment group.

It is also important to note that 7 of the 13 children in the behavioural treatment group who scored within the range of mental retardation at the intake evaluation scored within the average range on both the IQ and verbal IQ tests at the time of the follow-up evaluation. In the eclectic treatment group, only 2 of 12 children recorded this level of improvement.

While the study provides strong evidence in support of the effectiveness of behavioural treatment for improving the outcomes of children with autism, it is necessary to note the following limitations:

- the assignment of the children to the two groups was not completely random;
- the study consisted of small sample sizes; and
there were no direct quality control measures in relation to the treatment administered.

Itzchak et al measured and compared the changes in the cognitive level of young children with autism with the cognitive levels of children with developmental disabilities who participated in an early intensive intervention program. A total of 81 children were included in the study population, 44 with autism and 37 with other developmental disabilities. The mean age of the study participants was 25.9 months at commencement.

Evaluations of cognitive functioning were undertaken at the commencement of the intervention program and after one year of intervention. The progress of three groups of children was assessed. These three groups were defined based on their pre-intervention cognitive levels:

- normal – IQ of over 90
- borderline – IQ between 70 and 89
- impaired – IQ between 50 and 69.

The one year evaluation found that the IQ scores of children in the autism group increased significantly more than the scores recorded by the children with developmental disabilities. Improvements in IQ scores were also found to be significantly correlated with a reduction in the severity of autism symptoms, mostly in relation to stereotyped behaviours. Significant improvements were also noted in the autism group in relation to social, communication and play behaviours.

The results of this study emphasise the effectiveness of early intensive intervention for young children with autism across all cognitive levels. While the intervention was found to improve cognitive ability in all children in the study population, the improvement in the children with autism was found to be significantly greater than that achieved by children with other developmental disabilities. The study also recommended that longitudinal follow-up research be conducted to further investigate the relationships between early intensive intervention and cognitive levels and severity of symptoms in individuals with autism.

Anan et al examined the efficacy of the Group Intensive Family Training (GIFT) program in terms of its impact on outcomes for children with ASD. The GIFT

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program is a 12 week, 180 hour parent-training program for preschool-aged children with autism that involves individual mentoring of parents in the application and implementation of behaviour analytic techniques. The study population consisted of 72 children and their parents, with the children being aged between 25 and 68 months.

The key results from the study were as follows:

- average gain of eight standard score points on the Mullen Early Learning Composite;
- average gain of five standard score points on the Vineland Adaptive Behaviour Composite; and
- 14% and 11% of the children moved from the impaired to the non-impaired range on the Mullen and Vineland composite scores respectively.

While these results indicate that the GIFT program has a positive impact on the outcomes of preschool-aged children with autism, the results must be interpreted with caution given the lack of a control group to allow for comparison of outcomes.

A study by Perry et al assessed the outcomes of a population of 332 children with autism aged from two to seven years who were enrolled in a large, community-based Intensive Behavioural Intervention (IBI) program. Of this population, 58% of the children had a diagnosis of Autistic Disorder, 14% had PDD-NOS and 28% had less specific diagnosis of ASD/PDD.

The IBI program involves intensive early intervention treatment for children with autism, using behaviourally based methods. The programs typically involve the provision of 25 to 40 hours of intervention per week over a period of one to three years with curriculum being comprehensive and individualised for each child.

Psychological assessment file data was assessed to determine the impacts of the program on the development of the children. Two sets of data were available – one obtained from an entry assessment (within three months of the commencement of the program) and another assessment conducted at the child’s exit from the program.

The results obtained from the analysis of the data were as follows:

- the data clearly showed a statistically significant improvement in autism severity throughout the population from intake to discharge from the program;

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• of the children classified in the mild/moderate autism range at intake, 41% improved so as to be in the non-autism range at discharge;

• of the children classified in the severe autism range at intake, 15% improved so significantly that they were classified in the non-autism range at discharge while 59% had moved to the mild/moderate classification;

• of the population of 332 children, 127 had recorded cognitive scores at both intake and discharge. These children showed a statistically significant improvement in their IQ estimate (average increase of 12 points);

• gains in IQ estimates of 15 points or more were found in 39% of children, with 17% making particularly significant gains of over 30 IQ points; and

• significant improvements were also recorded across the population in terms of adaptive behaviour skills, communication and socialisation skills and rates of development, however children recorded lower scores for daily living skills at exit compared to entry into the program.

While this study provides support for the IBI program in terms of its impact on cognitive levels and development of children with autism, it does have the significant limitation of lacking a comparison group of similar children who received no treatment or another form of treatment. This means that the changes in performance cannot conclusively be attributed to the IBI program.

Itzchak and Zachor conducted a study assessing the changes in autism diagnostic classification resulting from intervention in very young children. The study also assessed pre-treatment indicators of outcomes for children with autism. The population for the study included 68 children diagnosed with autism aged between 18 and 35 months. The children underwent two evaluations – the first prior to the commencement of intervention and the second after one year of the intervention program.311

At the second evaluation, two distinct groups were identified within the population:

• an unchanged group of 53 children who maintained the same autism classification as they had recorded in the first evaluation; and

• an improved group, which included 15 children who recorded a changed classification or had moved off the autism spectrum.

The improved group were found to have recorded significantly higher gains in all of the outcome measures, including cognitive functioning, adaptive skills and a reduction in stereotyped behaviours. The key result from this study was that 22% of the participants had moved from an initial classification of autism to either ASD (19%) or off the autism spectrum (3%) after one year of intervention services.

Eikeseth et al undertook a further study in 2009. The purpose of this study was to assess the relationship between the intensity of supervision and the outcomes achieved by preschool aged children with autism who receive intensive early behavioural intervention. The study group consisted of 20 children with autism who were provided with, on average, 34.2 hours of intervention services per week for 50 weeks of the year.

The intensity of the direct supervision provided was varied for each child, with the intensity ranging from 2.9 hours per month to 7.8 hours per month. The study found a significant correlation between the intensity of supervision and IQ improvement scores. The linear regression that was estimated based on the results showed that, on average, participants recorded a gain of 0.21 IQ points for each additional hour of supervision, however these results are to be interpreted with caution.

Hayward et al undertook a study to assess the progress of a group of children with autism who received treatment for a mean of 36 hours per week on a one-to-one basis under the UCLA Applied Behaviour Analysis (ABA) program after one year of treatment. Two types of service provision were compared:

- an intensive clinic-based treatment model with all treatment personnel
- an intensive parent-managed treatment model with intensive supervision only.

The sample populations of the two groups were 23 and 21 children respectively. A non-concurrent multiple baseline design across the study participants (with a sample group of 13 children) were also assessed to examine whether the progress recorded was associated with the ABA treatment or cofounders.

The key results from the study were as follows:

- both groups recorded significant improvements in their IQ, visual-spatial IQ, language comprehensive levels, expressive language skills, social skills, motor skills and adaptive behaviour;

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• there were no significant differences between the two groups in terms of any of the measures at the follow-up assessment; and

• the mean IQ for participants in both groups increased by 16 points between the intake and follow-up assessments, with 50% of study participants gaining 15 IQ points or more while 39% gained between 1 and 14 IQ points.

While this study provides strong support for the positive effects of one year of ABA treatment for children with autism, the lack of an alternative treatment or no-treatment control group for comparison is a major weakness and prevents any credible conclusions being drawn from the study in terms of the impacts of the ABA treatment on child development.

Dawson et al conducted a study in order to evaluate the efficacy of the Early Start Denver Model (ESDM) for toddlers with autism.314 The ESDM is a comprehensive developmental behavioural intervention for improving outcomes of toddlers diagnosed with ASD. The study involved the assignment of 48 children with ASD aged between 18 and 30 months to two groups – one receiving ESDM intervention for a two year period and the other being referred to community providers for intervention commonly available in the community.

The two-year evaluation of the study population revealed that compared with the children who received community intervention, the children in the ESDM group showed significant improvements in their IQ scores, adaptive behaviour skills and autism diagnosis. Significant improvements were observed in relation to receptive and expressive language abilities, with children in the ESDM group recording improvements of 18.9 and 12.1 points respectively compared to the respective improvements of 10.2 and 4 points recorded by the children in the comparison group.

The children in the ESDM group also maintained their rate of growth in adaptive behaviour relative to a normative sample of normally developing peers (i.e. children without autism), while the comparison group showed significant delays in adaptive behaviour. The children in the comparison group also recorded average declines in standard scores that were twice the magnitude of the declines recorded by children in the ESDM group in the domains of socialisation, daily living skills and motor skills.

The evaluation also demonstrated that children in the ESDM group were far more likely to experience an improvement in development and functioning sufficient to result in a change in their autism diagnosis than those children in the community.

intervention group. After two years of treatment, the diagnosis of 29.2% of the children in the ESDM group had changed from Autism Syndrome to PDD-NOS. This proportion compared to only 4.8% in the comparison group.

A study by Green et al assessed whether the positive results of previous small trials on early intervention for social communication for children with autism would apply in a larger setting. A total of 152 children diagnosed with core autism aged between 2 years and 4 years and 11 months were randomly assigned to a PACT intervention program or treatment as usual at specialist centres. Of the entire population, 77 children were assigned to the PACT group and 75 to the treatment as usual group.

The outcomes of the children were evaluated after 13 months of treatment. The key results from the evaluations were as follows:

- severity of autism symptoms were reduced by 3.9 points on the ADOS-G algorithm for children in the PACT group compared to a 2.9 point reduction in the treatment as usual group;
- the effect was positive in relation to the parental synchronous response to the children, child initiations with parents and for parent-child shared attention; and
- the effects on directly assessed language and adaptive functioning in school were minimal.

While the study indicated that the PACT program produces strong benefits in terms of the improvements in parent-child social communication, it was not considered that the evidence from the evaluation was sufficient to recommend the addition of the program to the treatment as usual intervention program that is in place for children with autism.

In conclusion, there is a significant body of evidence available in the literature to support the positive impact of intensive early behavioural intervention on the cognitive and development levels of young children with autism. Several studies have assessed the impact on child development, social skills, adaptive abilities, language skills, and cognitive levels with the majority finding that intensive early intervention has positive outcomes.

However, there is still a lack of evidence available in relation to the longer term impacts of early intervention on outcomes (i.e. adult and lifelong outcomes). There still exists only a small number of studies that have assessed the adolescent and young adult outcomes of individuals with autism who were provided with early intervention

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services. This gap in the evidence makes it difficult to draw definitive conclusions regarding the impact of early intervention on the lifelong outcomes for individuals with autism. However, there is significant evidence available to indicate that it is highly likely that early intervention improves lifelong outcomes and therefore avoids a proportion of the total costs attributable to autism.
C  Cerebral Palsy

The following summarises our review of studies that have examined the efficacy and/or effectiveness of early intervention for children with Cerebral Palsy.

The theory behind the use of early intervention treatments to improve outcomes in children with neurological conditions such as Cerebral Palsy is that early intervention is effective in training the child’s brain to overcome the disability while the brain is still developing (i.e. in the first few years). However, the evidence base supporting the use of early intervention techniques to treat children with Cerebral Palsy is relatively weak, as has previously been noted by Turk.\(^{316}\)

There are no US longitudinal studies that would help us understand lifelong issues, the impact of early interventions later in life, or risk for persistent or new adverse health outcomes in individuals with CP.

Of the previous studies on the benefits of early intervention for children with Cerebral Palsy, several have found no statistical evidence for its effectiveness. For example, Turnbull reported that there was no supporting analysis for the effectiveness of early intervention with regards to its aim of preventing or minimising fixed deformity and maximising function.\(^{317}\)

Also, in a study examining the effects of early motor intervention in 50 children, 23 of which had Cerebral Palsy, Mahoney, Robinson and Fewell concluded that the intervention had very limited effects.\(^{318}\) A study by Orton, et al on the impact of early intervention programs on preterm infants found that while early intervention was found to improve cognitive outcomes at infant age and at preschool age, the benefit was not sustained at school age. This observation suggests that the benefits of early intervention are restricted to short-term gains in cognitive outcomes.\(^{319}\)

A study by Ustad, Sorsdahl and Ljunggren on the effects of intensive physiotherapy in infants with Cerebral Palsy found the effect of intensive physiotherapy to be inconclusive, with only one of the five children included in the study showing significant improvement following the delivery of two four-week periods of daily


physiotherapy. It is also of significance that less than half of the individual goals set at the commencement of the study period were met over the two intervention periods.320

There are however, some studies that provide limited evidence for the benefits of early intervention treatments for children with Cerebral Palsy. For example, in an outcomes study including 20 children with Cerebral Palsy with a mean age of 32 months, the effect of an early intervention program, which included 30 minutes of massage or reading twice a week for a 12 week period, were assessed. The results of this study were as follows:

- children that received massage therapy showed fewer physical symptoms, including reduced spasticity, less rigid muscle tone, and improved fine and gross motor functioning;
- the children that received massage therapy also demonstrated improved cognition, social and dressing scores on the Developmental Profile and also showed more positive facial expressions and less limb activity during face-to-face interactions; and
- few developmental measures increased for the reading group over the 12 week study period, with only improved language and feeding scores recorded.321

Benefits of early intervention were also reported in a study conducted by Ohgi, et al which involved 23 high-risk low birthweight infants, 12 of which were included in the early intervention program and 11 of which made up the control group. The findings suggested that an early intervention program has beneficial effects on neonatal neurobehavioural development in low birthweight infants. The improvements observed in the individuals that received the early intervention services included:

- reduction in irritableness and fussy behaviour;
- higher capacity for maintaining stable-state organisation in the face of increasing levels of stimulation;
- higher capability for state-regulation in their ability to move when crying; and
- reduction in stressful behaviour.


However, in noting these improvements it is important to recognise the limitation that is imposed by the size of the sample used in the study.

Stewart et al conducted a study in Canada assessing the effectiveness of a therapy service provided to children with special needs transitioning from pre-school to kindergarten. The study group consisted of 13 families of children aged three to six years, with 37.5% of the children having been diagnosed with Cerebral Palsy. The participants were provided with occupational and physical therapy services over a 10 month period. The program also included parent education services. An evaluation was conducted following the conclusion of the therapy period, with the key outcomes being:

- children met or exceeded goals set by therapists and parents;
- parents’ perceptions of and satisfaction with the therapy were higher than the provincial average; and
- qualitative data from interviews with parents and service providers was supportive of the therapy.

While these outcomes indicated that the therapy had a positive impact on the children’s ability to transition to kindergarten, the small sample size means that the results must be interpreted with caution.322

King et al also conducted a study assessing the effectiveness of an early intervention therapy for children with special needs. The study included 50 children aged 5 to 12 years, 52% of which were diagnosed with Cerebral Palsy, who had attended an average of 17 therapy sessions over a six month period. The study used goal attainment scaling to examine whether the children had achieved their therapy goals in the functional areas of communication, school productivity and mobility, with follow-up assessments conducted five to six months after the completion of the intervention treatment.

The findings from the follow-up assessments suggested that the therapy sessions were successful in improving the functioning of children with special needs in the school setting, with children showing statistically and often clinically significant improvements in mean functional status and individual goal attainment. In particular, the findings suggested that speech-language, occupational and physical therapy led to functional improvements in communication, school productivity and mobility. While

the results from this study were positive, it is important to note that no random control group was available for comparison.323

There have also been several studies which have assessed the short-term impacts of specific early intervention treatments provided to children with Cerebral Palsy. These studies involve specific treatments being administered to children with Cerebral Palsy, normally for the purpose of achieving narrow objectives relating to the child’s functioning (e.g. reduced spasticity, increased mobility in one limb, etc.).

Harbourne et al conducted a study comparing two intervention treatments designed to improve sitting postural control in children with Cerebral Palsy.324 The study involved a randomised longitudinal study of 35 infants with delays in achieving sitting in addition to 15 infants with typical development (control group). All infants involved in the study were under two years of age. The infants with delays in achieving sitting were assigned to two treatment groups – a home intervention program or a perceptual-motor intervention program.

The results from this study indicated significant differences between the two intervention groups, with the infants that received perceptual-motor intervention recording the more significant improvements. The key results from the study were as follows:

- by the end of the intervention, 20% of the infants in the home program group crawled, compared to 40% of the infants in the perceptual-motor intervention group;
- both groups made progress against the GMFM and the Centre of Pressure measure, with the perceptual-motor intervention group recording more significant progress against the latter measure; and
- both the home and perceptual-motor intervention groups recorded significant improvements in GMFM sitting subscale scores, with an average improvement of 20 percentage points, which is greater than expected for the simple maturation of a child with Cerebral Palsy over the equivalent period of time.

The key conclusion from the study was that perceptual-motor, child-focused intervention provides greater flexibility and adaptability of the child’s ability to sit for


young children with Cerebral Palsy, and that this has the potential to translate to further improvements in motor development.

A study by Stearns et al assessed the effects of Constraint-Induced Movement Therapy (CIMT) on the hand skills and muscle recruitment of children with spastic hemiplegic Cerebral Palsy.\textsuperscript{325} CIMT is a therapeutic intervention using a constraint on the less-affected limb and intensive use of the hemiplegic extremity. The purpose of this study was to determine whether CIMT therapy, delivered over a two week period, could improve hand function and underlying muscle activation in children with Cerebral Palsy. The study included six children with hemiplegic Cerebral Palsy and assessed children’s outcomes based on grip and pinch strength, dexterity tests and electromyography (EMG). Outcomes were measured prior to, immediately following, and three months after the conclusion of the intervention treatment.

Consistent with previous studies, the results demonstrated significant improvements in hand skills. The key results from the study were as follows:

- grip and pinch strength improved immediately following the intervention treatment and continued to improve at the three-month follow-up;
- manual dexterity improved from the short-term intense CIMT intervention, with significant gains seen immediately following intervention; and
- muscle activation during strength measures of grip and pinch showed mean increases in both shoulder and elbow activation immediately and three months after the intervention period.

While this study demonstrates the benefits that can be achieved from CIMT in relation to hand movement among young children with spastic Cerebral Palsy, it is important to note the significant limitations of the study, including the small sample size, lack of a control group and short time period over which outcomes were measured.

Another study assessing the impact of an individual physical therapy treatment on the motor functioning of children with Cerebral Palsy was conducted by Martinsson and Himmelmann. This study examined the effect of straddled weight-bearing on hip migration percentage\textsuperscript{326} and muscle length in non-ambulatory children with Cerebral Palsy. Weight-bearing treatment refers to daily, controlled, supported standing for


\textsuperscript{326} Hip migration percentage is a measure of the extent of hip displacement experienced by children with Cerebral Palsy.
children who are unable to stand on their own. Participants in this study stood upright in maximum tolerated hip abduction and hip and knee extension for thirty to ninety minutes per day for a one year period.

The study participants that received the intervention after surgery recorded the largest decrease in migration percentage, with those using straddled weight-bearing as a preventative measure also demonstrating significant improvement. The study also found that the intensity of treatment had a significant effect on the outcomes achieved. Children who received the intervention treatment for ninety minutes per day recorded far greater benefits than children who only received thirty minutes of intervention per day. The key conclusion from the study was that straddled weight-bearing may reduce hip migration percentage or prevent an increase in the migration percentage and preserve muscle length in children with Cerebral Palsy.

Mattern-Baxter, Bellamy and Mansoor conducted a study assessing the effects of intensive Locomotor Treadmill Training (LTT) on young children with Cerebral Palsy, particularly in relation to gross motor skills related to ambulation, walking speed and endurance. The study included six children with Cerebral Palsy who received treadmill training three times per week in one hour sessions. The key results from this study were as follows:

- the treadmill speed of all children in the study increased by at least 100%, with one child’s speed increasing by 500% over the intervention period;
- the study population recorded significant decreases in their ten metre walk test times and significant increases in their six minute walk distance test; and
- the three children who were ambulatory with supporting devices at the commencement of the study made relatively larger gains compared to those children who were non-ambulatory.

The results of this study provide preliminary evidence that LTT can improve outcomes in children with Cerebral Palsy under the age of four years. The results also suggested that improvements in gross motor skills for children with lower levels of functioning and higher levels of spasticity may necessitate a more intensive LTT program in order to achieve these benefits. In noting the results of this study it is important to note the very small sample size, the lack of a control group, and also the lack of homogeneity within the study population.


Mattern-Baxter, Bellamy and Mansoor’s article also included a review of past studies that have assessed the impact of locomotor ambulatory training on children with Cerebral Palsy. The studies included in this review are summarised in the following table.

Table C.1 Studies assessing the impact of locomotor training on children with Cerebral Palsy

<table>
<thead>
<tr>
<th>Study author/s (year)</th>
<th>Study details</th>
</tr>
</thead>
</table>
| Dodd & Foley (2007)           | • Clinically controlled study of 14 school-aged children with moderate to severe impairments  
                                | • Improvements in walking speed and endurance                                    |
| Provost et al (2007)          | • Study of six children with mild impairments                                 |
|                               | • Significant improvements in Energy Expenditure Index and gait speed          |
| Schindl et al (2000)          | • Three month intervention treatment for ten school-aged children              |
|                               | • Statistically significant improvements in standing, walking, running and jumping under the Gross Motor Function Measure |
| Begnoche & Pitetti (2007)     | • Study of a group of six children with GMFCS levels ranging from I to V       |
|                               | • Improvements in gross motor function and endurance                          |
| Cherng, Liu, Lau & Hong (2007)| • Study of eight children with a mean age of 4.5 years and GMFCS levels of II and III who underwent a 36 week intervention program |
|                               | • Significant improvements in gross motor function and stride length           |
| Richards et al (1997)         | • Study of four non-ambulatory infants                                        |
|                               | • LTT provided three to four times per week over a four month period           |
|                               | • All children in the study showed improved gross motor function while two attained independent walking |


Goal setting is another specific type of intervention administered for young children with Cerebral Palsy. Ostensjo, Oien and Fallang’s study assessed the effectiveness of goal-oriented rehabilitation in 13 children with mild to moderate Cerebral Palsy. The intervention consisted of a nine month rehabilitation program consisting of two blocks of the setting and implementing of specific goals. The results of the study were largely positive, with a high proportion of goals being achieved and parents’ perception of child performance demonstrating a positive change.

Another treatment that has become increasingly common for young children with Cerebral Palsy is the injection of botulinum toxin a (BTX-A). This treatment blocks the release of acetylcholine at the neuromuscular junction, causing selective,


330 Acetylcholine is a major neurotransmitter in the nervous system that activates muscles.

331 The neuromuscular junction is the synapse responsible for the initiation of action potentials across the muscle’s surface, ultimately causing muscles to contract. The signal passes through the neuromuscular junction via the neurotransmitter acetylcholine.
temporary muscular chemodenervation.\textsuperscript{332} The purpose of this treatment is to improve short-term motor functioning in children with spasticity. One of the key benefits of the treatment is to either postpone or improve the efficiency of future orthopaedic surgeries.

A study by Molenaers et al evaluated the influence of gait analysis and BTX-A injections on the timing, prevalence and frequency of orthopaedic surgery.\textsuperscript{333} The study involved a retrospective review of 424 children with Cerebral Palsy born between 1976 and 1994. The children were separated into three groups, as follows:

- group one consisted of 122 individuals that were managed throughout the study period according to best practice guidelines in orthopaedics;
- group two consisted of 170 individuals who, in addition to the treatment administered to group one, also received input from gait analysis; and
- group three consisted of 132 individuals, who received input from gait analysis and BTX-A injections, in addition to being managed in accordance with best practice guidelines.

The prevalence of orthopaedic surgeries in the three groups was assessed at different stages over the study period (from ages three to nine). The key results were as follows:

- the progression of orthopaedic surgery was found to be significantly different among the three groups;
- only 10\% of the individuals in group three had undergone a surgical procedure by the age of seven, compared to 27\% in group two and 52\% in group one; and
- orthopaedic surgeries were delayed in group two relative to group one, while group three recorded a significant decrease in the prevalence of surgeries compared to the first two groups.

The key conclusion from the study was that the introduction of gait analysis postpones the first orthopaedic surgery in children with Cerebral Palsy, while BTX-A injections further delays and reduces the frequency of surgery procedures.

\textsuperscript{332} Muscular chemodenervation is a technique where a chemical is used to paralyse a muscle or group of muscles.

Another study assessing the benefits from BTX-A injections for children with Cerebral Palsy was conducted by Desloovere et al. This study assessed motor function in children with Cerebral Palsy following multilevel BTX-A treatment by evaluating its effects on the gait patterns of children with spastic Cerebral Palsy. The study consisted of 30 children with a mean age of 6 years and 11 months and GMFCS levels ranging from I to III. The study group was matched against a control group, also consisting of 30 children, which were provided with identical treatment, with the exception of the BTX-A injections.

The motor development status of the study participants was assessed at a mean time of one year and ten months following the treatment using a three-dimensional gait analysis. The analysis revealed that the control group showed a significantly more profound pathological gait pattern than the group that had received the BTX-A injections. The BTX-A injections were found to result in a gait pattern less defined by secondary problems.

The findings from this study suggest that a multilevel approach for BTX-A treatment has beneficial effects on the natural course of the length of proximal muscles. There is also evidence of a lower incidence of crouch associated with the treatment. The study also suggests that children that receive BTX-A treatment are likely to develop a gait pattern that is less defined by bony deformities (which can only be successfully managed with orthopaedic surgery) common in children with spastic Cerebral Palsy. A key implication from these findings is that multilevel BTX-A injection treatment can minimise the need for complex surgery at a later age in addition to enhancing the quality of life for children with spastic Cerebral Palsy.

While several past studies have provided evidence of the short-term benefits of targeted early intervention treatments for children with Cerebral Palsy, at this stage the evidence supporting the longer term benefits of early intervention is relatively weak. While the current evidence provides support for the effectiveness of early intervention in improving certain outcomes, there is currently no support for early intervention leading to improved long-term outcomes for individuals with Cerebral Palsy.

Consideration needs to be given as to how these gaps can be best addressed in order to be able to make a case for increasing the level of funding available for early intervention services for children with Cerebral Palsy. This was noted by King et al, who noted that the next research step should be to use the knowledge gained in more rigorously designed studies to provide greater confidence regarding the causal role of

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early intervention.\textsuperscript{335} This is particularly the case regarding the longer term impacts of early intervention on the level of functioning in individuals with Cerebral Palsy.

\textsuperscript{335} King, et al (2000).
D Hearing impairment

The following summarises our review of studies that have examined the efficacy and/or effectiveness of early intervention for children with hearing impairment.

The most common treatment for children with severe or profound hearing loss is the fitting of amplification devices in the form of hearing aids or cochlear implants. Early screening programs play a significant role in the early treatment of Permanent Childhood Hearing Impairment (PCHI) due to the importance of early detection in terms of the outcomes that are achieved. In terms of early intervention treatments, the most applied form of intervention is Auditory-Verbal Therapy (AVT).

D.1 Importance of early detection

The early treatment of PCHI has regularly been linked to improved outcomes in relation to communication and language abilities, mental health and future employment prospects. Historically, there has been a lack of scientific evidence substantiating these benefits, as is demonstrated by the following statement from the United States Preventative Services Task Force in 2001:

> There were no prospective studies that directly examine whether earlier intervention result in improved speech, language, or educational development.

The majority of past research studies have focused on comparing the impact of earlier detection and intervention on child development (i.e. 3 to 6 months after birth) as opposed to intervention and treatment at a later time in the child’s development (i.e. 2 to 3 years of age or later). There is a significant base of evidence supporting the hypothesis that the earlier and more efficiently a child with a hearing impairment is provided with access to meaningful sound, the better the opportunity that will be provided to the child to develop spoken language, literacy and academic skills.

The outcomes of past studies indicate that hearing loss in children should be detected as soon as possible after birth and that intervention should be initiated by six months of age to achieve optimal speech and language development. For example, in a study by Calderon, it was found that children that received intervention by 6 to 12 months

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obtained significantly better outcomes than those that received intervention after 12 months.\textsuperscript{340}

The table below provides a summary of the studies that have compared the effectiveness of early intervention at different stages of a child’s development.

### Table D.1 Summary of studies assessing the effectiveness of early intervention at various stages

<table>
<thead>
<tr>
<th>Source</th>
<th>Study details</th>
<th>Results</th>
</tr>
</thead>
</table>
• Speech, language and auditory skills assessed at time of exit from program  
• Home-based program involving weekly visits and use of a Total Communication approach focusing on language development, auditory skills and speech production  
• Two study groups – one included 80 children at 36 months; the other included 28 children at 45 to 88 months | • Testing demonstrated that the earlier the children received intervention the better their scores in relation to expressive and receptive language and auditory discrimination  
• Results indicated that identification and intervention by 6 months is critical for improved language outcomes  
• Age of intervention also significantly related to auditory skill performance  
• For the second group, clearest difference was language development with those that received intervention earlier recording significantly higher scores  
• The following all recorded trends in favour of the group receiving earlier intervention – early reading skills, expressive and receptive language, behaviour problems, social-emotional development and maternal communication |
| Kennedy, et al (2006) | • Study of 120 children with bilateral permanent hearing impairment and a mean age of 7.9 years  
• Study assessed the language ability of children after early detection. | • Confirmation of impairment by 9 months was associated with higher scores for language as compared with nonverbal ability  
• Speech scores did not differ significantly between those who were exposed to newborn screening or early confirmation and those who were not  
• Overall conclusion was that early detection was associated with higher scores for language but not for speech in mid-childhood |
| Moeller (2000) | • Study examined the relationship between the age of enrolment in intervention and language outcomes at 5 yrs of age  
• Group of 112 children with hearing loss who were enrolled in a comprehensive intervention program included in the study | • Statistically significant negative correlation was found between the age of enrolment and language outcomes  
• Children who were enrolled earliest (by 11 months) demonstrated significantly better vocabulary and verbal reasoning skills  
• Regardless of degree of hearing loss, early-enrolled children achieved scores that approximated those of non-impaired peers |
| Yoshinaga-Itano (2003) | • Comparison of developmental outcomes of children who had been early-identified with hearing loss in Colorado, US  
• Early identification defined as first six months | • Children who were early identified and had early initiation of intervention services had significantly better vocabulary, general language abilities, speech intelligibility and social-emotional development  
• Two other studies conducted in Nebraska and Washington State reported similar findings |
| Yoshinaga-Itano, et al (1998) | • Conducted a study to compare the language abilities of earlier and later- | • Participants’ receptive and expressive language abilities were measured using the Minnesota Child |

These studies clearly demonstrate the benefits of early detection and intervention in terms of its impact on early child development. The results also demonstrate that the earlier the identification and intervention occurs, the more significant is the positive impact on child development in areas such as language development, vocabulary skills and social functioning.

While these studies are useful for demonstrating the importance of early identification and intervention, they do not provide any evidence of the actual benefits of early intervention services relative to the scenario in which hearing impaired children do not receive any intervention. These studies have also not assessed the long term outcomes achieved by children with PCHI that receive early intervention. This represents a gap in terms of the supporting scientific basis for early intervention in children with PCHI.

In the absence of this information it would be necessary to make assumptions regarding the impact of childhood outcomes on outcomes into adulthood. For example, if early intervention results in a child achieving similar communication, social and educational outcomes to its non-hearing impaired peers, it is possible that similar outcomes can be expected in adulthood (in areas such as employment, social participation and independent living), particularly if those outcomes are not being influenced by other comorbid conditions. Ideally, however, studies of hearing impaired adults that have received early intervention are necessary to bridge this gap.

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341 This may not be possible to determine as it is likely that all children that are identified as having PCHI are subject to some form of early intervention.
D.2 Auditory-Verbal Therapy

Studies have also been conducted assessing the effectiveness of AVT interventions performed on young children with severe or profound hearing loss. It has been reported that with early detection, amplification and effective individualised AVT, up to 80% of children born deaf can potentially be successful in mainstream education and society.\(^\text{342}\)

Auditory-verbal interventions involve individualised, diagnostic sessions that include the use of hearing technology with the aim of acquiring listening as a primary modality to facilitate the development of spoken language. The method is based on the notion that most children with hearing loss can learn to communicate through spoken language if provided with appropriate amplification in addition to listening and language stimulation. The box below provides a summary of the Listen & Talk Programme - a significant auditory-verbal therapy intervention program that is provided in the Singapore General Hospital.

**Box D.1 The Listen & Talk Programme at the Singapore General Hospital**

The Listen & Talk Programme was established in July 2001 in the Department of Otorhinolaryngology of the Singapore General Hospital. The therapy provided under the program combines the three disciplines of audiology, speech-language pathology and the teaching of the deaf. The program uses the standardised curriculum of the Auditory-Verbal International as a guide.

Children included in the programme are fitted with an appropriate amplification device upon diagnosis of their hearing impairment. A major component of the programme is the training and support that is provided to parents. Parents and caregivers are trained in how to develop their child’s listening and language skills through participation in weekly individualised parent guidance sessions. Parents also receive weekly targets in relation to audition, speech, language, cognition and communication. Therapists and parents jointly conduct sessions in the comfort of the family’s home, with an increased focus placed on family activities and interests. Parent Groups are also held once every six weeks to provide additional education and support.

The multidisciplinary team responsible for administering the Listen & Talk Programme comprises medical professionals, audiologists, auditory-verbal therapists, a medical social worker and a psychologist. There is also the potential for therapists to collaborate with physiotherapists, occupational therapists, speech therapists and school educators when required.


There is an emerging body of research supporting the effectiveness of AVT for improving outcomes in children with severe to profound hearing loss. In 2004, Eriks-Brophy conducted a review of the research that had been conducted to date. This review concluded that few empirical studies had been conducted assessing the

communication and academic outcomes of children who had participated in AVT, and that those studies that had been conducted were plagued with methodological difficulties and inconsistencies, making the research very difficult to interpret. In particular, it was concluded that, based on the research undertaken to date, it was not possible to conclude that a direct cause-effect relationship exists between AVT and documented outcomes.

As a result of these methodological issues, the majority of the studies assessed were classified as Class III evidence (i.e. the lowest class of scientific evidence). The table below provides an overview of those studies that were assessed in this review.

Table D.2 Overview of studies considered in 2004 review by Eriks-Brophy on AVT

<table>
<thead>
<tr>
<th>Authors and year</th>
<th>Study outcomes</th>
<th>Assessment of scientific robustness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goldberg &amp; Flexer (1993)</td>
<td>Survey study examining efficacy of AVT programs in US and Canada, Majority of respondents identified themselves as successfully functioning</td>
<td>Rated as the lowest class of evidence, Issues identified included descriptive responses, self-reporting, No cause-effect relationships could be inferred</td>
</tr>
<tr>
<td>Robertson &amp; Flexer (1993)</td>
<td>Survey study requesting parents to provide test scores of reading development for school-aged children with pre-lingual hearing loss who were educated through AVT, 30 of 37 children scored at 50th percentile or higher on a variety of reading tests</td>
<td>Rated as lowest class of evidence, Results were anecdotal, No cause-effect relationships could be inferred</td>
</tr>
<tr>
<td>Roberts &amp; Rickards (1994)</td>
<td>Survey of graduates of an Australian integrated auditory/oral pre-school, Positive outcomes were reported – 83% of participants perceived their academic progress to be average to above average</td>
<td>Rated as the lowest class of evidence, Issues identified included pre-selected group, self-rating, No cause-effect relationships could be inferred</td>
</tr>
<tr>
<td>Lewis (1996)</td>
<td>Descriptive, retrospective study examining relationships among hearing levels, hearing status of parents, educational management, non-verbal IQ and reading age levels, Individuals with severe to profound hearing loss attained high levels of reading achievement by the time they left school</td>
<td>Rated as the lowest class of evidence, Major issues identified included lack of details regarding the early intervention treatment and the measures and methods used to evaluate progress</td>
</tr>
<tr>
<td>Wray, Flexer &amp; Vaccro (1997)</td>
<td>Study examining classroom performance of children who learned spoken language through AVT using a questionnaire which was supplied to teachers, 16 of 19 children who had attended the program were fully included in local schools and read at or above grade level</td>
<td>Rated as the lowest class of evidence, Issues identified were similar to the methodological constraints identified for the previous studies</td>
</tr>
<tr>
<td>Rhoades &amp; Chisholm (2000)</td>
<td>Study examining global language growth rates in children who had received intensive AVT for a period of 1-4 years</td>
<td>Rated as Class II scientific evidence (as opposed to the lowest, Class III), Authors did not imply that it was AVT alone</td>
</tr>
</tbody>
</table>

While the studies in the above table indicate general support for the use of AVT to improve hearing and language outcomes for children with severe to profound hearing loss, methodological difficulties limit the extent to which a direct cause-effect relationship can be observed between the therapy and documented outcomes. Eriks-Brophy therefore noted the need for more sophisticated and controlled research examining outcomes for graduates of AVT programs within frameworks incorporating the high standards associated with scientific evidence to illustrate the effectiveness of early intervention.344

In a survey study conducted between 1996 and 1998, Diller, Graser and Schmalbrock analysed the advancements in the auditory-verbal skills of infants suffering hearing loss of 90dB or more who underwent AVT in the Federal Republic of Germany. The study comprised of 103 children with profound hearing impairments who were younger than 24 months at the commencement of the study. The key outcomes from the study were as follows:

- the development rates of approximately 50% of the children were such that their progress and speed in hearing and language learning was comparable to children with normal hearing;
- two-thirds of the children whose hearing and language skills developed normally used a cochlear implant (the remaining third used hearing aids);
- the majority of children who wore a cochlear implant were also generally better able to acknowledge a spontaneous sound and auditory language from their surroundings;
- almost all children whose hearing devices were classified as being correctly adjusted exhibited rates of hearing development consistent with children with normal hearing; and

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The study found a highly significant relationship between consistent AVT and the normal development of hearing abilities.\(^{345}\)

The table below presents the results of previous studies that have been conducted on the outcomes of auditory verbal therapy.

<table>
<thead>
<tr>
<th>Authors and year</th>
<th>Study details</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rhoades &amp; McCafferey (2002)</td>
<td>Four year longitudinal study with 40 children</td>
<td>Found significant language growth and higher levels of linguistic competency</td>
</tr>
<tr>
<td>Wray et al (1997)</td>
<td>Study of 19 children with hearing impairments that had experienced A-V Therapy</td>
<td>Found that 16 of 19 children in sample group read at or above their grade level, with 44% reading at above average levels and their teachers rating them as having strong skills in areas of social behaviour, class participation, attention and academic skills</td>
</tr>
<tr>
<td>Robertson &amp; Flexer (1993)</td>
<td>Survey of 37 children with hearing impairments</td>
<td>Found that the majority read in the average range or higher compared to normally hearing children</td>
</tr>
<tr>
<td>Durieux-Smith et al (1998)</td>
<td>Study of 65 adolescents aged over 14 years who had received A-V Therapy as preschoolers</td>
<td>Results indicated that children who had received intervention could function effectively within the school and community environment, achieving scores within the average range on measures of communication, self-perception and academic skills</td>
</tr>
</tbody>
</table>


A study recently conducted by Dornan et al represents a more scientifically robust approach to assessing the outcomes from AVT for children with hearing impairment than the studies reported above. This study investigated the outcomes over a 50 month period for 19 pairs of children, one grouping with impaired hearing (the AVT group) and one group with normal hearing (the typical hearing group). The pairs were matched for language age, receptive vocabulary, gender and socioeconomic status. The study used a range of tools to assess speech, language, reading, mathematics, academic achievement and self-esteem.\(^{346}\)

The key outcomes from the study were as follows:

- the AVT group exhibited positive outcomes in early assessments in terms of their rate of progress in language and speech skills which were maintained at the 50 month assessment;

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• receptive vocabulary progress was found to be slower in the AVT group at the earlier assessment, however progress was found to have accelerated significantly at the 50 month assessment such that the rate of development for the AVT group was similar to that of the typical hearing group;

• the AVT group maintained standard score levels for receptive and expressive language which were similar to results for the typical hearing group;

• in the AVT group, 79% of participants scored within the typical range or above for language skills at the 50 month assessment (compared to 100% for the typical hearing group), with the AVT group achieving mean total language scores that were only 2.1 months less than the mean chronological age;

• positive results were also recorded for the AVT group in relation to reading and mathematics skills; and

• self-esteem levels were not significantly different between the two groups and were predominantly high for both.

While the results from this study indicate that it is highly likely that the combination of cochlear implant use and AVT may have positively influenced the level of speech and language skills achieved by children with impaired hearing, it is important that participants’ development levels continue to be monitored. The study noted previous research which has found that language development rates for a group of 85 adolescents with cochlear implants did not keep pace with their normal hearing peers at 15-18 years.

Although the results of the study by Dornan et al are positive in terms of the impact of AVT for children with hearing loss, the documented outcomes are not able to be generalised for the following reasons:

• both groups are mainly from families of a moderate to high socioeconomic level, exposing the study to the problem of self-selection. Higher socioeconomic status is also typically associated with higher language and reading levels and better academic performance;

• the documented outcomes are not necessarily applicable to children with comorbidities such as Cerebral Palsy; and

• the relatively small number of participants in the study.

Evidence can also be found supporting the effects of early AVT for individuals with hearing loss in a study by Bodmer et al which assessed speech scores in 445 adults that had been fitted with cochlear implants. The results of the study indicated two distinct
groups within the population - poor performers and excellent performers. The most significant finding was that for those adults that had suffered pre or peri-lingual deafness, 75% of the excellent performers had received AVT compared to only 21% of the poor performing group. This resulted in the conclusion that AVT, when implemented in early childhood, results in auditory neural programming that facilitates speech recognition after cochlear implantation.

There has been a significant body of research conducted over the past decade which has demonstrated positive outcomes for hearing impaired children as a result of AVT when combined with early identification and the fitting of cochlear implants. While this research is useful in terms of demonstrating the positive impact of early intervention on the speech and language outcomes achieved by children in the early years of schooling, there still exists a gap in the evidence in terms of the extent to which these positive outcomes are maintained by AVT graduates into adult life. Future research should be targeted at this gap. However, the current body of evidence still provides strong support for the positive impact of early intervention for children with hearing loss.

D.3 The LOCHI Study

Removing the current gap in the scientific evidence will require long-term outcome studies to be undertaken to assess the impact of early detection and intervention. The Longitudinal Outcomes of Children with Hearing Impairment (LOCHI) study, which is currently being undertaken by Hearing CRC in collaboration with National Acoustic Laboratories (a division of Australian Hearing), represents an example of such a study.

The LOCHI study, which commenced in 2005, includes 477 participants across New South Wales, Victoria and Queensland. The criteria for inclusion in the study were that participants were born between December 2002 and August 2007 and first received amplification before three years of age. Of the 477 participants, 328 are using hearing aids and 149 cochlear implants (83 unilateral and 66 bilateral). The breakdown of the severity of hearing loss across the participants is as follows:

- 16% mild
- 35% moderate

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347 Peri-lingual deafness occurs when an individual becomes hearing impaired during the development of speech and language.

20% severe

29% profound.

Participants are to be assessed at 6 and 12 months from study commencement, and then at the ages of three, five and eight.  

The aim of this study is to establish an evidence base for the speech, language, functional, psycho-social and educational outcomes of children who use hearing aids and/or cochlear implants. The study also set out to:

- quantify the effect of a range of factors, including age of intervention, on child outcomes;
- relate etiology to child outcomes; and
- track individual development of child outcomes.

The following results have been determined from the preliminary analysis of the study participants:

- analysis at 6 months after fitting suggests that children who received intervention before 8 months of age developed auditory comprehension at age-appropriate levels while children who received later intervention revealed deficits in these skills compared to non-impaired peers;

- current analysis strongly suggests that more normal language acquisition is achieved by children who are identified earlier, however the effect of age of intervention on long-term outcomes is still uncertain, with further study and analysis required; and

- having acknowledged the previous point, it is important to note the fact that no change was observed in the mean rate of language acquisition for both the early and later-identified children at the time of the 6 and 12 month post-fitting assessments, suggesting that early differences in language acquisition rates between the two groups are being maintained.

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Later assessments have found that at three years of age, the severity of hearing loss has a greater effect on language acquisition and development rates than the age of intervention (i.e. fitting). The study has also found that children who received an implant before 12 months of age developed expressive and receptive language within the range of normal hearing peers when measured at 12 months after implantation and at three years of age. Impact of the age of intervention on long-term speech production and perception, language, education and social development remains to be examined.\textsuperscript{352}

Visual impairment

The following summarises our review of studies that have examined the efficacy and/or effectiveness of early intervention for children with VI.

Behl, White and Escobar conducted a study to determine whether the intensity of an early intervention program would produce better outcomes in children with VI in terms of the measures of child and family functioning. A program involving weekly, home-based, family-focused interventions was compared to a cheaper program involving 12 parent group meetings without any direct intervention provided to the child. The study included 35 children with VI with a mean age of 13.8 months. Approximately two-thirds of the children had moderate VI with the remaining one-third having severe VI.

From the data collected over a 12 month period, it was determined that the impact of the more intense program on the measures of child and family functioning were negligible. However, it was noted that this finding was potentially attributable to children with VI requiring much more intensive intervention services than the weekly program. The study concluded that while the more intensive program did not yield benefits in excess of those observed under the cheaper, less intense program, it would be premature to conclude that more intensive intervention was not more beneficial for child or family functioning later in the child’s development.

A 1998 paper by Beelmann and Brambring evaluates a project providing early intervention and family counselling with infants and preschoolers that are blind in Germany. It examines the implementation and effectiveness of the project. The sample includes ten children in the project group (that received the intervention) and 40 children in a control group (importantly, this group was also receiving early intervention). Family characteristics were broadly matched and there was no evidence of other intellectual impairments in the children. The children were examined at various stages between 12 and 36 months.

The early intervention delivered by the project was based on home visits by a team comprising psychologists and a special education teacher. Parents were also given guidance and training on interactions with their child, as well as problem-oriented counselling. The average duration of the intervention was 24 months. It focussed on


orientation, fine motor skills and gross motor skills. The focus of interventions and counselling changed as the child grew older.

The results showed that full-term children in the project group performed markedly better than the control group up to 30 months. The differences had decreased at 36 months due to ‘ceiling effects’ in the project group (for example, the project group were already attaining 48.2 out of 58 points on the Orientation and Mobility scale by 30 months). The differences between the outcomes of the project and control groups were lower for the pre-term children.

Overall, this study provides evidence of a successful EI program that is intensive, individualised and impairment-specific, with a high level of parent involvement. The key findings in terms of the optimal approach to intervention were:

It seems to be favourable to (a) implement an intensive early intervention in the child’s home; (b) establish a close coordination between developmental assessment and intervention planning in the sense of a criterion-oriented early intervention; (c) provide an impairment-specific promotion of development, paying particular attention to the children’s orientation and mobility performance; and, finally, (d) include a high level of various forms of parent involvement, such as instruction on adequate social interaction and intervention for the children as well as intensive counseling oriented toward the needs of parents.

D’Allura conducted a longitudinal study of 13 preschool children with VI to determine the potential of early intervention to enhance social interaction skills in young children. The study assessed the effects of reverse mainstreaming in combination with a cooperative learning strategy on social interaction patterns. The children with VI were placed in two classes – one an integrated class consisting of both VI and non-impaired children and the other a self-contained class, including only children with VI (the second class served as the comparator group).

The key results from the study were as follows:

- solitary play was the predominant category of behaviour in the self-contained class, with children in this class spending almost three times as many minutes in solitary play compared to children with VI and the non-impaired children in the integrated class;


• the predominant category of behaviour for children in the integrated class was “begins interaction with peer”, which accounted for 31% of the behaviours exhibited by children with VI;

• children with VI in the integrated class increased their level of interaction with peers from 5% of the time to more than 20%, which was comparable to the results recorded for their sighted peers; and

• the percentage of interactions initiated with peers by children with VI increased significantly in the integrated class.

These results indicate that the implementation of a cooperative learning strategy and integration of preschool children with VI with non-impaired children can produce material benefits in terms of the ability of children with VI to interact socially with peers.358

Simmons identifies the core process for early intervention for children with VI as mediation, or trying to create, improve or facilitate a connection between the child and their environment.359 Success depends on more than understanding the process, which starts with the characteristics of the child and its unique developmental mode:360

The learning of young blind children is best understood, not by comparing it with that of the sighted majority, but by analysing the implications of their particular sensory provision. Blind children use their four senses, and sighted children their five, to construct their reality.

Simmons identifies three salient points of intervention and the particular problems they can create for mediation, being:

• early bonding (visual contact is central to this);

• contact with professionals; and

• exploration – mediation involves providing rich environmental opportunities via objects and interactions with the mediator:361

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Early exploration by the child requires extensive and intensive mediation; everything that the child will not naturally encounter must be brought to within reach or earshot. Mediators must adopt a more proactive style than is required for sighted children because the child’s spontaneous behaviour offers few clues to his needs or interest. There is no gaze, pointing, or movement to a target or perceived object. To compensate for this lack of clues, mediators must attend more consciously and reflectively to the task of bringing the child’s surroundings to him/her.

Lanners et al examined early intervention for children with Cerebral VI, which is a temporary or permanent visual loss caused by a disturbance of the posterior visual pathways and/or occipital lobes. At the time, this was still a relatively new field of study.

This study sought to make a connection between the neuro-ophthalmological assessment and rehabilitation strategies that can be used to improve visual skills. It examined a group of children who had attended a rehabilitation treatment in Italy at an early intervention centre attended by children from birth to four years of age.

The level of impairment of visual capacity was severe. All of the children were also affected by specific neurological disorders. 59 were severely impaired and 17 had medium or slight intellectual disability. 15 cases showed the typical findings of Cerebral Palsy.

The study concluded that a key role of early intervention is to assist sensory integration. For cognitive and motor development to be harmonised, the child needs simultaneous tactile, auditory and visual information.

Elisa et al observe that knowledge of the development of a child that is blind has been relatively limited. It is known that vision affects many aspects of early development, including bonding, wakefulness, balance, gross and fine motor functions, spatial concepts and language and learning. Sight represents an ‘incentive’ for all voluntary skills.

They identify ‘reach on sound’ as an important part of development. This is when a child that is blind is able to grasp an object that has been presented exclusively through the medium of sound. This study examined 20 children that were blind. It reinforced the importance of the ability to reach on sound, identifying it as a condition of, and

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catalyst for, subsequent developments. It is an organiser of mental and motor experience, for example, once a child mastered reach on sound, self-initiated mobility was then facilitated.

The authors conclude that early intervention is of critical importance. Knowledge of development issues, such as the importance of reach on sound, can ensure that appropriate guidelines for effective interventions can be implemented. They also noted that the program needs to be personalised according to the type and severity of the impairment.

Erickson et al examined practices to develop emergent literacy in children with VI. They noted that there had been no empirical investigations of emergent literacy intervention practices.

‘Emergent literacy’ is the developmental process beginning at birth where reading and writing skills are established. Language and concept development can be delayed in children with VI for a number of reasons, including early interactions with caregivers. Children with VI have less opportunity to explore the world around them and need to help develop senses and hand skills that increase the child’s opportunity to explore their environment:

Without a focus on the early development of senses and hand skills, young children with visual impairment and blindness may not be able to engage fully in emergent literacy learning.

The purpose of the study by Erickson et al was to examine emergent literacy intervention practices and understand what works. It is a qualitative study based on observing two practitioners at work with children in the US. Three key themes emerged, showing the depth and breadth of skills required to promote emergent literacy.

First, family centred practices are important, giving parents the skills and tools to become the teacher and assisting them in forming a good relationship with their support workers. Awareness of the needs of the caregiver is also important. Second, language and concept development is important, assisting the child to learn to explore the environment. Third, there should be a focus on senses as they relate to literacy.


This analysis showed that supporting emergent literacy in children with VI and blindness is complex. However, while it was only a qualitative assessment, it showed that early intervention strategies targeted at emergent literacy can be highly effective.
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**Down syndrome**


**Autism**


**Cerebral Palsy**


Hearing impairment


**Visual impairment**


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