

# **Long-term Disability Care and Support Scheme**

Submission to the Productivity Commission

August 2010



## Executive Summary

The purpose of this submission is to propose the inclusion of an Early Learning and Care program in the Australian Government's national scheme for the long-term care of people with disability. In addition to providing specialised childcare, this program will facilitate the provision of intensive Early Intervention (EI) services that are consistent with the Australian Government's Best Practice guidelines. The target group for these services is those children with a disability for which there is strong evidence of the benefits of intensive EI, with eligibility not determined by social and economic circumstances. This submission focuses on children with autism, noting the evidence supporting the potential for intensive EI to improve the long-term outcomes for these children. The proposed model may also be able to be applied for other disabilities where intensive EI has been shown to deliver benefits.

EI is the key process used to enable learning in children with autism. Delivery of this learning in a specialised childcare environment maximises the ability of the child to integrate with others and improve their potential life outcomes. The proposed Early Learning and Care program has been developed having regard to the Best Practice guidelines for EI that have been published by the Australian Government.

The objective of the proposed program is to develop a funding and service delivery model to be included in the National Disability Strategy that will facilitate the delivery of Early Learning and Care services that are consistent with the Government's Best Practice guidelines to children who have the potential to benefit from intensive EI, regardless of social and economic circumstances.

In order to achieve this objective, the program must include several important design features, including:

- diagnostic fidelity – important to ensure the precision of the process for identifying children eligible for inclusion in the Early Learning and Care program;
- eligibility criteria – two sets of criteria relating to the inclusion of disabilities in the program and the assessment of children with the appropriate disabilities, to ensure that those with the greatest potential to benefit from intensive EI are able to participate in the program;
- protocols for the accreditation of service providers – important to ensure that the services provided are consistent with Best Practice guidelines; and
- accountability mechanisms – compliance auditing and evaluation mechanisms to ensure that the integrity of the program is maintained.

These design features are necessary to ensure that the objectives of the program are satisfied and that the efficiency and effectiveness of government funding is maintained.

It is proposed that a defined process be followed for the provision of funding under the program. This process includes the diagnosis of the child, selection of an accredited service provider, and provision of funding to the selected service provider.

AEIOU has estimated the total cost of providing Best Practice Early Learning and Care services to children with autism at \$43,000 per child per annum.<sup>1</sup> Based on most recently available autism prevalence data and ABS population data, the total cost of the proposed program is estimated at between \$57.3 million and \$61.6 million per annum, with a point estimate of \$59.5 million.<sup>2</sup>

There are currently four sources of Federal Government funding available to families for the provision of Early Learning and Care services to children with autism – the Helping Children with Autism (HCWA) package, the Child Care Rebate (CCR), the Child Care Benefit (CCB), and the carer allowance.

The key problem with current funding arrangements is the exclusion of Early Learning and Care service providers from accessing the Inclusion Support Subsidy (ISS), which is provided under the Inclusion Support Program (ISP). The purpose of the ISP is to assist childcare service providers in the inclusion of children with additional development needs, with the ISS paid to support the employment of additional staff for children with high ongoing support needs. The maximum funding entitlement for centre-based caring under the ISS is \$16.19 per hour, to be provided at a maximum of 25 hours per week and 52 weeks per year. This equates to \$21,047 per child per annum.<sup>3</sup>

Non-mainstream childcare services are explicitly excluded from this program. The implication of this is that organisations providing Best Practice EI services to children with autism are not provided with funding under a program that is intended to facilitate the delivery of effective childcare services to children with disability. While this funding can be accessed for a child with autism, it is only to the extent that they are attending a mainstream childcare program. This results in parents having to choose between a fully funded childcare service that delivers sub-optimal outcomes and a Best

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<sup>1</sup> This corresponds to \$86,000 per child over the two year program period.

<sup>2</sup> There are a range of factors that could result in the actual cost of the program being higher or lower than the quoted estimates, including the prevalence of autism having increased or the implementation of more precise diagnostic criteria resulting in a reduction in the number of children diagnosed as autistic.

<sup>3</sup> It is important to recognise that a centre can be provided with one allocation of ISS funding to cover several children with additional development needs.

Practice service which requires significant private contributions due to a shortfall in government funding. This means that, in its current form, the ISP is failing to facilitate the delivery of childcare services to children with additional needs that optimises long-term outcomes.

It is estimated that families of children with autism are currently able to access between \$16,874 and \$23,940 in Federal Government funding (depending on the level of family income). This includes \$6,000 from the HCWA package, up to \$7,500 from the CCR, \$3,374 from the carer allowance, and between \$0 and \$7,066 from the CCB. This leaves an annual funding gap of between \$19,060 and \$26,126 per child.

Providing Early Learning and Care service providers with ISS-equivalent funding (\$21,047 per child per annum) would significantly reduce or even eliminate (depending on the level of family income) the gap between the cost of delivering Best Practice Early Learning and Care services to children with autism and the level of funding currently provided. It is considered that any residual funding gap could be met by a combination of funding provided by other sources (mostly private contributions).<sup>4</sup>

As a significant proportion of the total cost of the proposed program would be met by existing funding sources, the incremental cost of implementing the program to government is far below the total cost of the project, with the estimated range being \$28 million to \$30.1 million per annum (less the funding currently provided to eligible children under the ISS).

Given some children with autism are likely to be indirectly receiving funding under this program if they are attending a mainstream childcare facility, this existing funding would be redirected to this new program. This in turn further reduces the size of the funding gap that needs to be met by government.<sup>5</sup>

It is also important to note that several issues would need to be considered in the implementation of the proposed program. These issues include labour market impacts, supply lags, implications for existing service users, and the definition of government responsibilities.

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<sup>4</sup> Under the proposed funding model, low-income families will not be required to contribute to the cost of the program with middle to high income families expected to make a relatively small contribution.

<sup>5</sup> AEIOU estimates that approximately \$8.65 million in ISS funding is currently provided to children with autism. This reduces the incremental cost of the program to government to between \$19.4 million and \$21.5 million per annum.

While this submission focuses on an Early Learning and Care program for children with autism, it also provides a framework for the wider application of the proposed program and funding model to other disabilities. This general framework is as follows:

- develop Best Practice guidelines for the provision of Early Learning and Care services to children with the relevant disability;
- assess the prevalence of the disability in children;
- develop a service delivery model, having regard to the Best Practice guidelines;
- develop a funding model and assess the funding requirement based on the information available regarding prevalence; and
- develop and implement the necessary auditing arrangements for the program.

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## 1 Introduction

The Australian Government has stated that it is committed to developing a National Disability Strategy to enhance the quality of life and increase economic and social participation for people with disability and their carers. An exploration of alternative approaches to funding and delivering disability services with a focus on Early Intervention (EI) and long-term care is to be an important component of this strategy.

The Productivity Commission (PC) has been directed pursuant to Parts 2 and 3 of the *Productivity Commission Act 1998* to conduct a public inquiry into a national disability long-term care and support scheme. The inquiry was commenced in April 2010, with the PC's report to be submitted by 31 July 2011.

The purpose of this inquiry is to examine the following:

- how a scheme should be designed and funded to better meet the long-term needs of people with disability, their families and carers;
- how to determine the people most in need of support, the services that should be available to them, and service delivery arrangements;
- the costs, benefits, feasibility and funding options of alternative schemes;
- how the scheme will interact with the health, aged care, information care, income support and injury insurance systems;
- how any scheme should be introduced and governed; and
- what protections and safeguards should be part of the scheme.

The purpose of this submission is to propose the inclusion of a program for Early Learning and Care, which involves the delivery of Best Practice EI in a specialised childcare setting, in the national scheme for the long-term care of people with disability. In addition to providing specialised childcare, this program will facilitate the provision of intensive EI services that are consistent with the Australian Government's Best Practice guidelines to those children with a disability for which there is strong evidence of the benefits of intensive EI, regardless of social and economic circumstances.

This submission focuses on children with Autistic Disorder and Pervasive Developmental Disorder (PDD) (referred to as 'children with autism' for the remainder of this submission) as a case study, as there is strong evidence supporting the long-term benefits from intensive EI for this group.

This submission is structured as follows:

- section 2 details the Terms of Reference that are to be addressed in this submission
- section 3 provides an overview of Autism Spectrum Disorders and the prevalence of autism in children
- section 4 outlines the proposed service delivery model
- section 5 provides an overview of the design features of the proposed model
- section 6 outlines the governance and administrative arrangements
- section 7 discusses the current sources of funding and proposed funding arrangements underpinning the program
- section 8 addresses the relevant implementation issues
- section 9 concludes the submission.

## 2 Terms of Reference to be addressed

The Terms of Reference that have been provided to the PC for this inquiry cover a range of topics. Those that are to be addressed in Synergies' submission are as follows:

- consideration of the following specific design issues of any proposed scheme:
  - eligibility criteria, including proposed age limits, assessment and review processes;
  - coverage and entitlements (benefits);
  - the choice of care providers including from the public, private and not-for-profit sectors;
  - contribution of, and impact on, informal care; and
  - interaction with, or inclusion of, employment services and income support;
- consideration of governance and administrative arrangements for any proposed scheme including:
  - the governance model for overseeing a scheme and prudential arrangements;
  - administrative arrangements, including consideration of national, state and/or regional administrative models; and
  - implications for Commonwealth and State and Territory responsibilities;
- consideration of the costs and financing of any proposed scheme, including:
  - the costs in the transition phase and when fully operational, considering the likely demand for, and utilisation under different demographic and economic assumptions;
  - models for financing; and
  - contributions of Commonwealth and State and Territory governments; and
- consideration of the implementation issues of any proposed scheme, including:
  - changes that would be required to existing service systems;
  - workforce capacity; and
  - lead times, implementation phasing and transition arrangements to introduce a scheme with consideration to service and workforce issues, fiscal outlook, and state and territory transitions.

### 3 Autism Spectrum Disorder

The purpose of this section is to outline the nature of Autism Spectrum Disorder (ASD), the prevalence of ASD in young children in Australia, and also the economic and social costs incurred as a result of the disorder.

#### 3.1 What is ASD

ASD is a category of PDDs which includes a number of conditions including:

- autism itself
- Asperger's Syndrome (Asperger's)
- Childhood Disintegrative Disorder (CDD)
- Pervasive Developmental Disorder that is Not Otherwise Specified (PDD-NOS)
- Rett's Syndrome.<sup>6</sup>

ASD is a developmental disorder, primarily characterised by impairments in communication and social activity.<sup>7</sup> Restricted, repetitive and stereotyped patterns of behaviour are a typical feature of the disorder. The World Health Organisation provides the following definition:<sup>8</sup>

...autism encompasses the following areas of developmental abnormality:

- 1) Social relatedness: abnormal social relationships and social developments
- 2) Communication: failure to develop normal communication
- 3) Imagination: interests and activities that are restricted and repetitive, rather than flexible and imaginative.

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

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

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

<sup>7</sup> National Institute of Mental Health (2004). Autism Spectrum Disorders (Pervasive Developmental Disorders), [www.nimh.nih.gov/publicat/autism.cfm](http://www.nimh.nih.gov/publicat/autism.cfm), p 1.

<sup>8</sup> Basset, K., Green, C. & Kazanjian, A. (2000). Autism and Lovaas Treatment: A Systematic Review of Effectiveness Evidence. British Columbia Office of Health Technology Assessment, The University of British Columbia, p 2.

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

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

Rett Disorder is an extremely specific and rare sub-group of ASD. It is a genetic disorder of postnatal brain development that is caused by a single-gene defect and predominantly affects females. The final sub-group is PDD-NOS which applies to individuals who exhibit the features of autism but cannot be appropriately classified into one of the other sub-groups.<sup>9</sup>

### 3.2 Prevalence of autism

The most recent comprehensive autism prevalence study conducted in Australia is MacDermott et al (2007). According to 2005 Centrelink data provided in this report, the prevalence rate for autism in children aged between 0 and 5 years is 19.6-21.1 per 10,000 (a mid-point of approximately 20.3 per 10,000).<sup>10</sup> The study also quoted State and Territory prevalence estimates as high as 21.9 per 10,000.

Other sources have suggested that the prevalence of autism in children is far higher, with rates of 1 in 160, 1 in 150 and even 1 in 100 being reported.<sup>11</sup> 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.<sup>12</sup>

It is important to note that these prevalence estimates relate to all children with ASD. The target group for this proposal (children with Autistic Disorder and PDD-NOS) is only a sub-section of this group. As is discussed in section 4, the benefits of Early

<sup>9</sup> Muhle, R., Trentacoste, S. & Rapin, I. (2004). The Genetics of Autism, *Pediatrics*, 113 (5).

<sup>10</sup> MacDermott, S., et al (2007). The Prevalence of Autism in Australia: Can it be established from existing data? A report prepared for Australian Advisory Board on Autism Spectrum Disorders, p 31.

<sup>11</sup> See: Scott, Sophie. "Studies Show Increase in Autism Cases." *ABC News*. 23 July 2009. Web. 18 Mar. 2010. <<http://www.abc.net.au/news/stories/2009/07/23/2634744.htm>>; McCredie, J. "Early Intervention in Autism." *ABC*. 15 Oct. 2009. Web. 17 Mar. 2010. <<http://www.abc.net.au/health/thepulse/stories/2009/10/15/2714894.htm>>.

<sup>12</sup> *Autism Rates Soaring among Queensland School Children*. The Courier Mail, 9 Apr. 2010. Web. 2 Aug. 2010. <<http://www.couriermail.com.au/news/queensland/autism-rates-soaring-among-queensland-school-children/story-e6freoof-1225852008088>>.

Learning and Care services have only been established for this target group, not for all children with ASD. This emphasises the importance of diagnostic fidelity, with concerns being raised that behavioural problems are being confused with autism. This issue is discussed in detail in section 5.1.2.

Given the narrow definition of the target group it is considered that the range of 19.6 to 21.1 per 10,000 as presented in the 2007 report on the prevalence of autism in Australia represents the most appropriate prevalence estimate to be applied for this program. This equates to approximately 1 in 500 children, which is consistent with prevalence estimates used in overseas jurisdictions.

### 3.3 Economic and social costs of autism

There are a wide range of costs associated with ASD. These include direct costs such as increased healthcare expenditure; other tangible costs such as a reduction in employment and the costs incurred in providing informal care; and intangible impacts such as the adverse impacts on the quality of life of individuals with ASD and their families.

Synergies undertook an assessment of the economic costs of ASD in Australia in 2007. Table 1 provides an overview of the cost estimates generated by Synergies in this report.

**Table 1 Estimated costs of ASD per annum**

Category	Total cost (\$'000 Dec 2006) – low prevalence	Total cost (\$'000 Dec 2006) – high prevalence
<b>Direct costs</b>		
Healthcare	373,459	632,553
Social services	157,999	157,999
Education	117,155	210,632
<b>Other tangible costs</b>		
Employment	2,107,038	3,635,464
Informal care	950,963	1,776,908
<b>Intangible costs</b>		
Burden of disease	766,610	766,610

**Source:** Synergies (2007). Economic Costs of Autism Spectrum Disorder. AEIOU.

Overall, this suggests annual total costs of between around \$4.5 billion and \$7.2 billion per annum, with a mid-point of \$5.8 billion (in \$ December 2006). It is noted that the above table includes an estimate for the costs relating to autism associated with the provision of informal care. The impact of the proposed Early Learning and Care program on this cost category is discussed later in this submission. It is also important

to recognise that this study did not estimate several costs, including the costs of under-employment, the full costs of informal care, and the costs associated with family breakdown which include financial, health and social impacts.

## 4 Proposed service delivery model

This section provides the basis for the inclusion of the proposed Early Learning and Care program in the Australian Government's National Disability Strategy by providing an overview of the observed benefits of such a program for children with autism. This section also briefly considers the potential for the program to be extended to other developmental disabilities that are prevalent in young children in addition to outlining the Australian Government's Best Practice guidelines for the provision of EI services to children with autism.

### 4.1 Defining Early Learning and Care

The proposed Early Learning and Care program combines Best Practice EI with specialised childcare. EI is the key process used to enable learning in children with autism. Delivery of this learning in a specialised childcare environment maximises the ability of the child to integrate with others and improve their potential life outcomes, as well as providing important support for the family, including full employment participation and respite, with the child in a safe, regulated environment. Overall, such a program provides these children with the best chance of being able to successfully transition into a 'mainstream' school environment and deliver life-long benefits to these children and their families.

Children with autism are the key focus of this submission based on their status as a highly disadvantaged group in society in terms of economic and social outcomes<sup>13</sup> and also due to the strong evidence of the long-term benefits associated with the provision of intensive EI services for these children (see section 4.2.2 for the Australian Government's Best Practice guidelines for providing EI services to children with autism). It is possible that this Early Learning and Care model could also deliver benefits to children with other disabilities, however they are not explored in detail here.

A wide range of therapies and learning strategies are applied to pre-school aged children with autism. This is necessary because autism is a spectrum disorder (i.e. social and cognitive abilities and learning styles vary across sufferers). However, for children diagnosed as low functioning, only intensive, learning-based therapies are supported by a strong evidence base of success.

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<sup>13</sup> Synergies Economic Consulting (2007). Economic Costs of Autism Spectrum Disorder. AEIOU.



According to Stephens (2005), Best Practice EI for children with autism has the following important elements:<sup>14</sup>

- intervention should occur for over 20 hours per week;
- low student to adult ratio (preferably 2:1); and
- curriculum needs to be tailored to the individual needs of the child, be behaviour-based, and be developmentally sequenced.

## 4.2 Outcomes

There is a large body of evidence indicating that significant benefits can be achieved from the provision of intensive EI services to children with autism:<sup>15</sup>

Despite the lack of unequivocal scientific evidence, parents and practitioners have witnessed dramatic shifts in the competency of children such as those with ... autism when they participate in intensive, systematic early intervention programs.

The Box below provides an overview of a recently completed study that assessed the efficacy of an EI program aimed at toddlers with ASD.

### **Box 1 Study on the effectiveness of the Early Starter Denver Model**

G. Dawson et al (2009) recently completed a study on the effectiveness of the Early Starter Denver Model (ESDM), which is a comprehensive developmental behavioural intervention for improving outcomes of toddlers diagnosed with ASD. This study represents the first randomised, controlled trial that has been undertaken to demonstrate the efficacy of a comprehensive developmental behavioural intervention for toddlers with ASD.

The study involved 48 children diagnosed with ASD between 18 and 30 months of age. These children were randomly assigned to one of two groups for a two-year period:

- ESDM; or
- commonly available intervention supplied by community providers.

After the conclusion of the two year period, the children in the ESDM group showed significant improvements in IQ, adaptive behaviour and autism diagnosis. The most important results from the study were as follows:

- children in the ESDM group improved by 17.6 standard score points on average compared with an average improvement of 7 points in the comparison group, relative to baseline scores (ESDM children recorded a level of improvement over two and a half times that recorded by the comparison group);
- children in the ESDM group maintained their rate of growth in adaptive behaviour compared to a normative sample of non-ASD children, while the comparison group showed greater delays in adaptive behaviour; and
- children in the ESDM group were also more likely than the comparison group to experience a change in diagnosis from autism to PDD, not otherwise specified.

<sup>14</sup> Stephens, L. (2005). Early Intervention in Autism: Forging the Architecture for Change.

<sup>15</sup> Ramey, C. & Ramey, S. (1998). Early Intervention and Early Experience. American Psychologist, 53(2), pg 112.

These results underscore the importance of early intervention for young children with autism.

**Data source:** Dawson, G. et al (2009). Randomized, Controlled Trial of an Intervention for Toddlers with Autism: The Early Start Denver Model. *Pediatrics*, published online Nov 30, 2009.

Other documented evidence from the relevant literature regarding the positive outcomes from intensive EI for children with autism has cited the following benefits:

- improvement in intellectual and educational functioning;<sup>16</sup>
- gains in comprehensive, receptive<sup>17</sup> and expressive language skills;<sup>18</sup>
- significant improvements in behavioural symptoms to the point where some children were not classified as autistic according to the Childhood Autism Rating Scale (CARS);
- significant improvements in child-appropriate behaviour, mostly relating to sharp reductions in non-compliance;
- reduction in the number of children requiring special schooling;<sup>19</sup>
- improvement in communication and work and play behaviours;
- improvements in imitation, fine motor skills, gross motor skills and non-verbal conceptual skills;<sup>20</sup>
- significant improvements in daily living skills, adaptive behaviour, joint attention, and social interaction;<sup>21</sup> and
- benefits to both parents (higher level of satisfaction and less stress) and children from intensive behaviour analytic treatment.<sup>22</sup>

<sup>16</sup> Lovaas, O. (1987). Behavioural Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children. *Journal of Consulting and Clinical Psychology*, 55(1).

<sup>17</sup> Howard, J. et al (2005). A Comparison of Intensive Behaviour Analytic and Eclectic Treatments for Young Children with Autism. *Research in Developmental Disabilities*, vol 26.

<sup>18</sup> Swallows, G. & Graupner, T. (1999). Replicating Lovaas' Treatment and Findings: Preliminary Results. Paper presented at the meeting of the Autism Society of America, Kansas.

<sup>19</sup> Strain, P. & Hoyson, M. (2000). The Need for Longitudinal, Intensive Social Skills Intervention: LEAP Follow-Up Outcomes for Children with Autism. *Topics in Early Childhood Special Education*, Summer 2000, vol 20.

<sup>20</sup> Mesibov, G. (1997). Formal and Informal Measures on the Effectiveness of the TEACCH Programme. *Autism*, 1(1), pp 25-35.

<sup>21</sup> Salt, J. et al (2002). The Scottish Centre for Autism Preschool Treatment Programme. *Autism* 6(1), pp 33-46.

<sup>22</sup> Howard, J. et al (2005). A Comparison of Intensive Behaviour Analytic and Eclectic Treatments for Young Children with Autism. *Research in Developmental Disabilities*, vol 26.

The literature also points to the observable benefits associated with behavioural interventions for children with autism and the positive relationship between the intensity of the intervention and the outcomes achieved by children.<sup>23</sup>

The provision of intensive Early Learning and Care services to children with autism also produces significant benefits with respect to avoided costs associated with loss of productivity. The costs of autism associated with loss of productivity are two-fold. Firstly, children with autism typically have a significantly lower productive capacity throughout their adult lives relative to normal developing children. Second, the level of care required to be provided by the family will impact the ability of one or both parents, or the extended family, to participate in the workforce. Jarbrink and Knapp (2001) have previously estimated that parents of children with autism earn 20% less than other parents.<sup>24</sup> While many parents return to the workforce in a full capacity when their children attain school age, this is likely to be more difficult for parents of children with autism. This is reflected in the National Employment Standards in the *Fair Work Act 2009*, section 65 of which states that an employee that has responsibility for the care of a child with a disability may request a change in working arrangements.

As outlined above, the delivery of EI services within a specialised childcare setting is fundamental to improving the long-term outcomes for children with autism and their families.

First, delivery in such a setting (compared to say, home-based services) assists in facilitating learning in relation to communication, social interaction and play. Second, it also relieves the informal care burden on parents (and other family members). Apart from the impact on their ability to participate in the workforce, there is evidence to show that parents of children with autism suffer from considerably higher levels of stress, which can also contribute to family breakdown.<sup>25</sup> This can have significant and far-reaching effects for the family and the wider community. Third, children with autism and their parents can benefit from better integration of therapies, learning strategies, improved consistency and communication of goals, by having various professionals working closely together every day in the setting.

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<sup>23</sup> Eikeseth, S. (2001). Recent Critiques of the UCLA Young Autism Project. *Behavioural Intervention*, vol 16, p 250.

<sup>24</sup> Jarbrink, K. & Knapp, M. (2001). *Economic Impact of Autism in Britain*, Autism, 5(1).

<sup>25</sup> For example, refer: Warfield, M. (2005). Family and Work Predictors of Parenting Role Stress Among Two-Earner Families of Children with Disabilities, *Infant and Child Development*, 14; Seltzer, M., Shattuck, P., Abbeduto, L. & Greenberg, J. (2004). Trajectory of Development in Adolescents and Adults with Autism. *Mental Retardation and Developmental Disabilities Research Reviews*, vol.10; Loynes, F. (2001). *The Impact of Autism*, A Report Prepared for the All Party Parliamentary Group on Autism.

Overall, the proposed Early Learning and Care model can deliver significant benefits for children with autism and their families.

#### **4.2.1 Expansion of the program to other disabilities**

As outlined above, the focused delivery of Early Learning and Care services to children with disability (as is argued for in this submission) need not be limited to children with autism. Rather, there are several other developmental disabilities prevalent in children for whom the benefits of Early Learning and Care services are potentially significant and cost-effective (i.e. the benefits from improved long-term outcomes outweigh the costs of providing the services).

The provision of this program has the ability to deliver significant benefits for any disability that is prevalent in young children and affects learning, providing the services are delivered under a model that ensures the provision of consistent support with a focus on improving the socio-environmental factors that are affecting the children, as occurs in a specialised childcare setting. The main disabilities, in addition to autism, for which these benefits may be significant include:

- Attention Deficit Disorder (ADD)
- Developmental delay
- Intellectual disability
- Down syndrome
- Cerebral palsy
- Fragile X syndrome.

While autism has been selected as the target group for this submission, given the strong evidence for the benefits of Early Learning and Care services for children with autism, this submission also provides a framework for identifying opportunities to expand the proposed program and funding model to other disabilities. The general framework is as follows:

- develop Best Practice guidelines for the provision of Early Learning and Care services to children with the relevant disability;
- assess the prevalence of the disability in children;
- develop a service delivery model, having regard to the Best Practice guidelines;

- develop a funding model and assess the funding requirement based on the information available regarding prevalence; and
- develop and implement the necessary auditing arrangements for the program.

The cost of completing a systematic review of a disability to determine whether it is appropriate for inclusion in the proposed program is estimated at approximately \$50,000. It is proposed that this cost be absorbed by government.

#### 4.2.2 Best Practice guidelines

The Australian Government has published a set of Best Practice guidelines to be used to assess the value of EI programs for children with autism. These guidelines were developed based on available research and evidence on the effectiveness of EI practices for children with ASD and are designed to assist parents, carers and professionals in making decisions regarding the suitability of potential programs. An overview of each of the thirteen criteria included in these guidelines is provided in the Box below.

##### 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 care givers, 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.

**Source:** [http://www.health.gov.au/internet/main/publishing.nsf/Content/D9F44B55D7CA25780007A98BD/\\$File/autbres.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/D9F44B55D7CA25780007A98BD/$File/autbres.pdf)

It is important that any service delivery model aiming to facilitate the delivery of Early Learning and Care services to children with autism is developed with reference to these guidelines. The need for the program to involve an intensive, multi-disciplinary approach from qualified professionals means that home-based programs are not appropriate. These requirements mean that it is necessary for services to be provided under a specialised childcare setting in order to be consistent with the Best Practice guidelines.

The Australian Government's Best Practice guidelines for EI have been used as the basis for the development of the proposed Early Learning and Care program. The specific characteristics of this program are outlined in the following section.

## **5 Proposed Early Learning and Care program**

This section outlines the key design features of the proposed Early Learning and Care program in addition to assessing the interaction of the program with child care support schemes, the implications for informal care providers, and the cost of delivering the program.

### **5.1 Key design features**

#### **5.1.1 Objective**

The objective of the program is to develop a funding and service delivery model to be included in the National Disability Strategy that will facilitate the delivery of Early Learning and Care services that are consistent with the relevant criteria (in this case, the Australian Government's Best Practice guidelines for EI services for children with autism) to children with autism (with the potential to expand the program to include other disabilities for which the benefits of such a program can be clearly established). It is also the objective of the program that these services are delivered to eligible children regardless of social and economic circumstances.

The service delivery model and associated funding arrangements have been designed with the objective of maximising the long-term efficiency and effectiveness of government funding. In this case, efficiency refers to ensuring the optimal allocation of funding resources, while effectiveness relates to the extent to which service delivery models are robust, consistent with the relevant guidelines, and improve long-term outcomes for children with disability.

#### **5.1.2 Diagnostic fidelity**

Diagnostic fidelity relates to the precision of the process for identifying those children that are appropriate for inclusion in the Early Learning and Care program. Maintaining diagnostic precision is fundamental to the efficiency and effectiveness of the proposed program, as it is necessary to ensure that funding for the provision of intensive Early Learning and Care services is directed to those children that will derive significant long-term benefits.



Achieving diagnostic fidelity relies on the processes installed in relation to the assessment of applications for inclusion in the program. In relation to children with autism, this requires the establishment of teams capable of undertaking comprehensive multidisciplinary assessments, with evaluations undertaken to be consistent with the requirements identified under the 'Preparation' criterion in the Best Practice guidelines, which include the following:

- interviews with parents and care givers
- collection of information from all professionals involved in the care of the child
- paediatric, psychological and speech pathology examinations
- a multidisciplinary diagnostic assessment based on agreed criteria.

It is proposed that State-based teams be formed to undertake individual assessments (consistent with the above requirements, or any requirements relevant to the disability that is deemed to be appropriate for inclusion in the program) of children proposed for inclusion in the program.

### **5.1.3 Eligibility criteria**

There are two components to the eligibility criteria that would need to apply under the proposed program:

- a set of criteria for the inclusion of disabilities in the program
- a set of criteria for the assessment of children with the appropriate disabilities.

As has been previously discussed, it is considered that the Early Learning and Care program should include young children with any disability for which there exists strong evidence of the benefits of intensive EI. This will require a case-by-case assessment of developmental disabilities that are prevalent in young children (see section 4.2.1) to determine which are appropriate for inclusion in the program. An analysis of the costs of providing the necessary services and the magnitude of the long-term benefits should be central components of this assessment.

The second component of the eligibility criteria is the establishment of a set of criteria that children must meet in order to be considered eligible under the program. This should involve a regulated process under which children must obtain positive diagnoses for the disabilities targeted under the program. For example, State-based diagnostic assessment committees could be established which will assess each application individually. Upon receiving approval from the assessment committee, the



child will become eligible to receive Early Learning and Care services under the program.

These processes, combined with the previously discussed arrangements to ensure diagnostic fidelity, will be crucial to maintaining the integrity of the program and ensuring that government funding is allocated effectively and efficiently.

It is also important that social and economic circumstances are not taken into consideration when assessing whether a child is appropriate for inclusion in the program. This is necessary to ensure that the program is administered in a manner that ensures equality, so that all children that satisfy the necessary eligibility criteria are provided with the same level of services.

#### **5.1.4 Accreditation of service delivery models**

Establishing appropriate protocols for the accreditation of service providers is important to ensuring that the services provided to eligible participants are effective in achieving positive long-term outcomes consistent with Best Practice guidelines. Failure to establish the necessary protocols can result in the accreditation of organisations that provide services that are not consistent with the relevant criteria or the objectives of the proposed program.

There are two key elements to the framework to be established for the accreditation of service providers under the program:

- the development of requirements with which service providers must achieve compliance in order to become accredited; and
- the monitoring of accredited service providers to ensure that compliance with the established requirements is maintained.

The criteria and requirements that are established under the accreditation process need to ensure that in order to obtain accreditation, a service provider must be able to clearly demonstrate that the services provided under its delivery model are consistent with the relevant criteria or guidelines (e.g. the Best Practice guidelines for EI services to children with autism).

The successful implementation of such a protocol will require the establishment of an evaluation committee with the ability to undertake a comprehensive assessment of an accreditation application.

In relation to the second element, it will be necessary for a team of experts to be established (potentially the same as the evaluation committee) to undertake compliance assessments of the services being delivered by accredited organisations.

This is necessary to prevent any accredited service providers from providing services that do not meet the specified requirements for accreditation.

These two elements in combination, along with the arrangements for ensuring diagnostic fidelity, will ensure that only Early Learning and Care services that are consistent with the relevant requirements are provided to eligible participants under the program.

### **5.1.5 Provision of funding**

The following is considered to represent a reasonable framework for the provision of funding under the Early Learning and Care program which has been outlined in the previous sections:

- Step 1: diagnosis of the child;
  - State-based teams complete multidisciplinary assessments to determine whether the child meets the necessary diagnostic criteria;
- Step 2: family is provided with information regarding accredited service providers;
  - following the diagnostic criteria being satisfied, the families of eligible children are provided with information regarding the service delivery programs of the accredited service providers that are located within a reasonable distance. If no such services are available, a list of accredited service providers in other locations will be provided. The necessary processes to provide this service are already available through the HCWA package (see section 7.1.1);
- Step 3: provision of assistance with selecting an accredited service provider;
  - advisors are made available to assist families in selecting the appropriate service provider for their child (autism advisors are already established by the Australian Government under the HCWA package);
- Step 4: selection of an accredited service provider;
  - based on the information made available and assistance from advisors, families select an accredited service provider for their eligible children;
- Step 5: provision of the actual funding;
  - funding for the particular child is provided to the selected accredited service provider while the child attends that provider on a per hour basis. This alleviates the administrative burden and enables service providers to use the

funding provided to meet children's needs. If for some reason the child is required to change to another accredited service provider, that funding is transferred to the new service provider; and

- Step 6: monitoring and review;
  - to facilitate the ongoing review and evaluation of the effectiveness of the Early Learning and Care program, the progress of each child in the program will be monitored and recorded.

## 5.2 Implications for informal care

The implementation of the proposed program would result in a significant proportion of the informal care that is currently provided to children with autism being replaced with formal care provided under the proposed service delivery model. As outlined previously, loss of productivity and family breakdown are two of the main costs associated with autism. The loss of productivity relates to the prolonged reduction in the levels of workforce participation by carers as a result of their informal care obligations. In addition to the loss of productivity for society, this results in a decrease in the standard of living of the individuals providing informal care.

There are also considerable costs incurred resulting from stress and family breakdown, which can be a common reality for families of children with autism. Family breakdowns have both direct and indirect impacts on the family and the wider community. Reducing the informal care burden by providing Best Practice EI in a specialised childcare setting significantly reduces the stress on families. This is not only in the short-term (while the child is in the program), but also in the long-term via the potential for material improvement in the lifelong outcomes for these children.

## 5.3 Cost of delivering the program

Table 2 provides a breakdown of the estimated cost of Early Learning and Care services by accredited organisations to eligible children with autism.

**Table 2 Cost of providing Early Learning and Care services to children with autism**

Cost category	Estimated cost per child per annum (\$)
Salaries and other staff costs	34,000
Administration costs	3,000
Site occupation costs (i.e. rent)	3,000
Consumables and other materials	3,000
<b>Total</b>	<b>43,000</b>

Source: Estimates provided by AEIOU.

The cost estimates provided in Table 2 assumes:

- full-time care for pre-school children with autism;
- a multidisciplinary approach with staff resources including early childhood teachers, occupational therapists, speech pathologists, psychologists and teacher facilitators;
- long day care provided for 40 hours per week, with the Early Learning and Care component of the program accounting for 25 hours per week;
- integration of therapy-based interventions into a comprehensive learning program including peer interaction;
- specific content of programs tailored to meet each child's individual needs;
- a comprehensive assessment process with children assessed on intake and again at regular intervals throughout the program in addition to regular parent interviews and the frequent evaluation and adjustment of programs; and
- facilitation of each child's transition into a mainstream educational environment.

The annual cost of \$43,000 per child per annum corresponds to a total cost of \$86,000 per child over the two-year program. To determine an estimate for the total cost of the proposed program it is also necessary to determine the number of children eligible to receive the services.

The most recently available Australian-based data on the prevalence of autism in pre-school aged children is summarised in section 3.2. Based on ABS population data as of June 2009 and the prevalence rates estimated for children aged between 0 and 5 years, the range of eligible participants is estimated from 666 to 716 per year.<sup>26</sup> For a two year period, the total number of eligible children ranges from 1,332 to 1,432.

Based on the above cost estimates, the range for the total annual cost of the provision of Early Learning and Care services to children with autism is \$57.3 million to \$61.6 million, with the mid-point estimate of \$59.5 million. It is important to note that this range is indicative given the nature of ASD and the uncertainty over the prevalence of autism in children.

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<sup>26</sup> This range was calculated using ABS population data as of June 2009 and the range of prevalence rates reported earlier in this submission. The ABS population data for the 0-4 years and 5-9 years age groups was used to provide an estimate of the number of children in each year (i.e. under 5 years of age). The prevalence rates were then applied to these figures to calculate the range of eligible children. This is an imperfect methodology for determining the number of eligible participants, however it is necessary given the lack of more specific age and prevalence data.

There are three factors that affect the estimated cost of the Early Learning and Care program presented in this submission, including:

- the discovery of a real increase in the prevalence of autism in children, as is suggested by some recent research, would increase the cost;
- an improvement in diagnostic practices enabling the earlier diagnosis of autism in children, would increase the cost; and
- the implementation of a greater degree of diagnostic fidelity under the proposed program resulting in a reduction in the number of children diagnosed with autism, suggesting that current diagnostic criteria are not sufficiently narrow, would reduce the cost.

It is also important to recognise that the incremental funding required for the program will be less than the estimated total cost, as a significant proportion of the total funding requirement will be redirected from existing funding sources. It is estimated that the additional funding requirement of the proposed program would be between \$19.4 million and \$21.5 million. A detailed discussion on the estimation of this funding requirement is provided in section 7.3.

Similar prevalence and cost assessments would need to be conducted for other disabilities assessed as appropriate for inclusion in the program.

## **6 Governance and administration**

The purpose of this section is to:

- establish the reason for government involvement in the provision of Early Learning and Care services to children with disability; and
- outline the governance and administration arrangements that would be necessary to ensure the integrity of the proposed program.

### **6.1 Reason for government involvement**

#### **6.1.1 Market failure and government involvement**

Government intervention in a market is considered appropriate where there is clear evidence of market failure. Market failure exists where there is an inefficient allocation of resources and occurs as a result of one of several factors, such as the provision of inefficient pricing signals due to the presence of externalities or the impact of one market participant holding significant market power.

While government intervention such as the implementation of taxes or subsidies also result in an imperfect outcome (i.e. the allocation of resources does not maximise efficiency), it is considered that if designed appropriately, these measures are able to produce a more efficient allocation of resources than under the scenario where the market failure is left unregulated.

Market failures often occur in the financing and delivery markets in the health care sector. This is primarily attributable to the imperfect pricing information that is provided to market participants. The current situation in the market for the financing and delivery of Early Learning and Care services to children with autism provides an example of this market failure. As is discussed in section 4, the long-term benefits from the provision of these services are such that their universal provision represents a more efficient allocation of resources. However, these services are currently not provided at the necessary level due to the magnitude of the funding requirement and the fact that a significant proportion of the future benefits are captured by the community rather than the individuals to which the services are provided.

The presence of inefficient pricing signals and resource constraints provides a clear indication of market failure in the market for the funding and provision of Early Learning and Care services to children with autism. It is therefore efficient for government to intervene and install mechanisms that will ensure the universal provision of these services to achieve the long-term benefits.

### 6.1.2 Current government responsibilities

It is proposed that the Early Learning and Care program outlined in this submission be implemented at a national level and be administered by the Australian Government. In implementing this program it will be necessary for the Government to consider the current break-down of responsibilities in relation to the provision of funding for Early Learning and Care services between the State and Federal Governments. This process will involve determining the appropriate role for State Governments under the proposed program.

The Box below provides an overview of the involvement of the Queensland Government in the provision of funding for EI services.

#### Box 3 Responsibilities of the Queensland Government in provision of funding for EI services

In Queensland, the *Disability Services Act 2006* sets out the framework under which the Department of Communities (Disability Services) is responsible for providing leadership in disability services and programs for people with a disability and their families and carers. The Act also sets the legislative basis for Disability Services' funding. Some of the services are delivered by Disability Services directly, while others are delivered by non-government organisations funded by Disability Services. Disability Services' scope of responsibilities includes early childhood services.

Disability Services supports families with a child aged up to six years who has or is at risk of a significant developmental delay and meets the criteria outlined in the Disability Services Eligibility Policy. The aim of this program is to enable families to strengthen their knowledge, skills and resources to improve the child's developmental learning and inclusion in the community. Over the period between July 2008 and March 2009, \$6.6 million was allocated to this initiative. In addition to this, as part of the national Autism Early Intervention Initiative, Disability Services has also provided support to non-government organisations to implement an effective state-wide early intervention framework. Autism Queensland and AEIOU were provided with around \$2 million under this program between July 2008 and March 2009.

The allocation of funds for disability services is based on the support needs of people with a disability and on priorities identified across the State. Priorities are determined by the National Policy Priorities and the Queensland Government Strategic Framework for Disability (2002-2005). Funding provided under the Queensland Government's Autism Early Intervention initiative has facilitated the delivery of nine new centres across Queensland. The Queensland Government has also recently announced a further \$1 million in recurrent funding for the provision of Early Learning and Care services to children with autism, taking its total annual funding contribution to \$3.3 million.

**Sources:** Disability Services Queensland (2009). Final Report July 2008 – March 2009. Queensland Government; *Palaszczyk Visits Rockhampton Autism Centre*. Queensland Government - Minister for Disability Services and Multicultural Affairs, 4 May 2010. Web. 30 June 2010. <<http://www.cabinet.qld.gov.au/mms/StatementDisplaySingle.aspx?id=69591>>; AEIOU.

It is clear that State Governments currently have a role in providing funding to facilitate the delivery of Early Learning and Care services to children with autism. The separation of responsibilities between the State and Federal Governments will need to be considered in the implementation of the EI program. This is discussed further in section 8.4.



## **6.2 Governance and administration**

### **6.2.1 Accountability mechanisms**

It is important that the necessary mechanisms are implemented to allow for an assessment of the extent to which the design features of the Early Learning and Care program are being upheld. This is particularly important in relation to diagnostic fidelity and to ensure that the services being delivered are consistent with the relevant requirements. Ensuring the accountability of the program is crucial to maintaining the efficiency and effectiveness of the proposed funding arrangements.

In addition to the mechanisms detailed above in relation to the eligibility criteria and accreditation of service providers, the proposed program must include:

- compliance auditing arrangements to ensure that the services being delivered under the program are consistent with the relevant requirements; and
- review arrangements to ensure that the implementation of the eligibility criteria is appropriate.

Failure to implement these mechanisms will render it impossible to assess the effectiveness and efficiency of the government funding being provided under the program. This has been a major problem with funding mechanisms and programs aimed at facilitating the provision of services to children with autism to date.

### **6.2.2 Evaluation of long-term performance**

In addition to maintaining the integrity of the program by ensuring that consistency with the design features is maintained, it is also important that arrangements are established to allow for the long-term evaluation of the performance of the program. This differs from the arrangements intended to ensure the accountability of the program in that it focuses on assessing the long-term outcomes that are achieved by the children provided with Early Learning and Care services.

The implementation of a long-term evaluation framework is important for ensuring that the service delivery models implemented under the proposed program are actually effective (i.e. optimise long-term outcomes for children with autism).

The Box below provides an overview of the elements that may be included in this evaluation framework.



#### Box 4 Proposed elements of an evaluation framework

An evaluation framework to assess the long-term performance of services delivered under the proposed program would need to include the following elements:

- there must be two separate groups of children included in the study:
  - the control group – children with autism not subject to the early intervention services that are being assessed;
  - the experimental group – children that are to be provided with early intervention services through the funding assistance provided under the package;
- treatment fidelity needs to be established. This involves:
  - the documentation of treatment procedures;
  - the provision of evidence demonstrating how procedures are consistently adhered to;
  - the provision of evidence on the involvement of staff and parents in the delivery of the Early Learning and Care services;
  - the identification and documentation of any other treatment that is being received by children in either the experimental or control group;
- outcome measures must be clearly specified. This means that:
  - measures should be focused on the improvements that are being targeted by the treatment;
  - where possible, measures should be standardised;
  - there should be full disclosure of the tests undertaken and how they are administered;
  - the same measures should be used pre- and post-treatment with any changes that are made documented (including why the change occurred and how this will impact the assessment);
  - if any child-specific objectives are established these should be documented in addition to the means by which performance against these objectives is to be assessed;
  - assessments should be undertaken by personnel that are independent to the actual treatment that is being assessed;
  - longer-term follow-up is highly desirable;
- where experimental and control groups are established for a study, the following should be noted:
  - it is desirable to include as many of the children who have access to the Early Learning and Care services provided by the funding assistance through the package as possible in the experimental group;
  - the nature of the control group is dependent upon the research question that is being examined. It may comprise children with autism that are not receiving Early Learning and Care services or children that are receiving other types of services. If the purpose of the study is to evaluate the benefits of the program against another form of early intervention, the latter is likely to be more appropriate;
  - the basis for determining the experimental and control groups should be fully documented; and
  - both groups should be of similar size and have children with a similar profile that is representative of the population of children with autism. A similar average age at entry is also deemed to be an important requirement.

Table 3 provides an overview of some of the evaluation tools that could be used to assess the performance of accredited service providers in terms of improving outcomes achieved by children with autism. It is proposed that outcomes be documented upon the entry of the child into the program, after one year of the program, and at the completion of the program.

**Table 3 Evaluation tools and estimated costs**

Evaluation tool	Outcome measures	Kit cost (\$)	Protocol cost/test (\$)	Admin. time
Mullens Scales of Early Learning	<ul style="list-style-type: none"> <li>• Visual receptive skills</li> <li>• Expressive language</li> <li>• Receptive language</li> <li>• Fine motor skills</li> </ul>	2,100	4.36	Approx 1 hr per child
Preschool Language Scales	<ul style="list-style-type: none"> <li>• Language milestones</li> </ul>	800	9.46	Approx 1 hr per child
Vineland Adaptive Behaviour Scales	<ul style="list-style-type: none"> <li>• Communication skills</li> <li>• Daily living skills</li> <li>• Social skills</li> <li>• Motor skills</li> <li>• Maladaptive behaviour</li> </ul>	265	2.96	Approx 1 hr per child

**Note:** It is estimated that after purchasing a kit, the cost of performing the assessments would be \$17 per assessment plus 3 hours of staff time.

**Source:** AEIOU.

The costs associated with assessing the outcomes achieved by children under the Early Learning and Care program using the evaluation tools included in Table 3 are estimated as follows:

- a one-off up-front cost of \$3,165 associated with the purchase of the evaluation kits; and
- a cost of \$17 plus three hours of staff time per assessment.

As the evaluation of the outcomes of children is an element of the Best Practice guidelines (see section 4.2.2), it is proposed that these costs be absorbed by accredited service providers. In addition to providing a mechanism to enable the outcomes achieved under the Early Learning and Care program to be documented, this would enable the provision of additional information to the next level of educators.

## 7 Funding

The purpose of this section is to identify the sources of government funding that are currently available to children with autism, in addition to highlighting the problems associated with current funding arrangements and outlining the proposed funding framework for the Early Learning and Care program.

### 7.1 Current funding arrangements

There are currently four sources of Federal Government funding available for the provision of Early Learning and Care services to children with autism:

- the Helping Children with Autism (HCWA) package
- the Child Care Rebate (CCR) and Child Care Benefit (CCB) allowances
- the carer allowance.

The following sections assess the amount of funding that is available from each of these sources.

#### 7.1.1 Helping Children with Autism package

The HCWA package involves a commitment to provide \$190 million in funding over a four year period to facilitate the delivery of services to children with ASD. The package commenced in July 2008 and will conclude at the end of June 2012.<sup>27</sup>

A funding assistance package to facilitate the delivery of EI services is one of the five elements of the HCWA package.<sup>28</sup> The aim of this funding assistance is to provide children with autism aged between 0 and 6 years with increased access to EI services. The program is intended to support the delivery of multidisciplinary evidence-based EI services with the goal of facilitating improved cognitive, emotional and social development in young children with ASD.

Each child is entitled to up to \$12,000 in funding under this package. This total can be used up until the child's seventh birthday, with an annual maximum of \$6,000.<sup>29</sup> The

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<sup>27</sup> There is no available information as to whether the package is to be extended beyond this date.

<sup>28</sup> The other four elements are Autism Advisors; PlayConnect Playgroups; Early Days family workshops; and an ASD website.

<sup>29</sup> Families who reside in an outer regional area or beyond, according to the Accessibility/Remoteness Index of Australia (ARIA+) classification, may also be eligible to access a one-off Outer Regional and Remote (ORR) Payment Outer of \$2,000 per eligible child to cover the additional expenses associated with accessing early intervention services.

Federal Government anticipated that over 7,000 children with autism would be provided with services under this package in 2009/10.<sup>30</sup>

### **7.1.2 Child Care Rebate**

The purpose of the CCR is to assist families with meeting the cost of childcare. The rebate covers 50% of out-of-pocket childcare expenses for approved childcare. The current level of the maximum rebate for eligible families is \$7,500 per child per year (pending legislation). This amount is indexed on an annual basis.

In order to be eligible for the CCR, families must use approved childcare and be eligible for the CCB. In order to be eligible for a rebate for over 24 hours of approved childcare services per week, families typically need to have passed the CCB 'Work, Training, Study Test', however families with a child with autism are exempt from this requirement.

### **7.1.3 Child Care Benefit**

The CCB is intended to assist families in meeting the cost of childcare services by linking family income to the level of assistance received. The magnitude of the CCB that is approved depends on three factors:

- the amount of approved childcare used
- the applicants' CCB percentage
- if the child is a school or a non-school child.<sup>31</sup>

Each year, the Government sets a standard hourly rate for childcare benefits. Each eligible family is then apportioned a percentage (can be more or less than 100%), depending on the individual circumstances of the family.

To qualify for the CCB, a family must typically meet an income test, with payments for approved childcare limited to 24 hours per child per week unless the family meets the 'Work, Training, Study Test'. However, parents that receive a carer allowance, which includes parents of a child with autism (see following section), are exempt from this test, and receive the CCB automatically. The current rate for a non school aged child is \$3.68 per hour (or \$184 per week).

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<sup>30</sup> Australian Government (2009). 'Families, Housing, Community Services and Indigenous Affairs Portfolio.' 2009/10 Budget Portfolio Paper No. 1.7.

<sup>31</sup> Child care benefit rates for school children are 85% of the rates for non-school children.

Where actual annual family income is less than \$37,960 or families are on income support, the maximum payment rate is applied. A zero rate is payable for the following thresholds:

- for 1 child in care - \$134,443;
- for 2 children in care - \$139,333; and
- for 3 or more children in care - \$157,329 plus \$29, 721 for each child after the third.<sup>32</sup>

#### **7.1.4 Carer allowance**

The carer allowance is a supplementary payment that is available to a parent or carer who provides additional care and attention on a daily basis for a child aged under 16 years with a disability. Parents of children with autism automatically qualify for the carer allowance as Autistic Disorder is on the list of recognised disabilities that are eligible for the program.

The total amount of annual funding available under the carer allowance is \$3,374.20 per annum. This includes fortnightly payments of \$106.70 and an annual carer supplement of \$600. Eligible families also receive benefits from having a health care card for the child. These benefits include additional refunds for medical expenses.

#### **7.1.5 Other sources of funding**

While the sources of funding detailed above could contribute to the costs of providing Early Learning and Care services to children with autism, other sources of funding are also required to meet the total cost. The sources relied upon currently include:

- State Government funding – provided to service providers on a periodic basis, typically to facilitate the delivery of new centres. The level of funding provided by State Governments is highly variable across the country;
- private philanthropy – contributions made by private sources, such as AEIOU's 10:40:600 program;<sup>33</sup> and

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<sup>32</sup> *Child Care Benefit*. Department of Human Services. Web. 10 Mar. 2010. <[http://www.centrelink.gov.au/internet.internet.nsf/payments/childcare\\_benefit.htm](http://www.centrelink.gov.au/internet.internet.nsf/payments/childcare_benefit.htm)>.

<sup>33</sup> AEIOU's 10:40:600 program involves a \$10,000 funding contribution from either an individual or an organisation. This \$10,000 contribution leverages a further \$30,000 in government support and parent fees, which provides sufficient funding for an additional placement. AEIOU estimates that this contribution can provide an average lifetime cost saving of \$600,000 per year for each year the child participates in an AEIOU program.

- parent contributions – parents are required to meet the gap between government and private contributions and the cost of service provision.

## **7.2 Problems with current funding arrangements**

### **7.2.1 Inclusion Support Subsidy**

A key funding source available to children with a disability is the Inclusion Support Subsidy (ISS), under the Inclusion Support Program (ISP). However, non-mainstream childcare services are ineligible for funding.

The ISP is a component of the Inclusion and Professional Support Program (IPSP). The purpose of the ISP is to assist childcare service providers in the inclusion of children with additional development needs. The target group for the ISP includes children with ongoing high support needs and children with disability.

The ISS is paid to support childcare services to include children with high ongoing support needs so that they can be cared for in environments with typically developing peers.<sup>34</sup> The ISS can be used for the following purposes:

- employ an additional worker in the childcare service
- pay a relief worker to accompany an eligible carer on out-of-home excursions
- provide an additional payment to home-based carers.

The following services are eligible to obtain funding under the ISS:

- all Australian Government childcare services that are approved for the CCB, including:
  - long day care
  - outside school hours care (including vacation care)
  - occasional care
  - family day care
  - in home care services
- childcare services funded under the Budget Based Funding Program, including:
  - flexible/innovative services

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<sup>34</sup> The ISS replaced the Special Needs Subsidy Scheme (SNSS) and the Disabled Supplementary Service Payment (DSSP) from 1 July 2006.

- mobile childcare services
- multi-functional aboriginal children's services
- indigenous playgroups
- indigenous outside school hours care and enrichment programs
- innovative childcare service centres.

The maximum funding entitlement for centre-based caring under the ISS is \$16.19 per hour, to be provided at a maximum of 25 hours per week and 52 weeks per year. This hourly rate is determined by the Department of Education, Employment and Workplace Relations (DEEWR) and is indexed on an annual basis. The current hourly rate equates to a maximum entitlement of \$21,047 per child per annum. However, it is important to recognise that a centre can be provided with funding to cover several children with additional development needs (i.e. it is possible for a childcare centre to have several children with additional needs but only be provided with one allocation of ISS funding).

### **7.2.2 Exclusion of Best Practice service delivery from ISS**

The stated purpose of the ISS, according to IPSP Guidelines as of July 2009, is to support childcare services in the inclusion of children with high ongoing support needs so that they can be cared for in environments with typically developing peers. The Guidelines also state that the ISS is not to be used to provide assistance to a child to access non-mainstream childcare, such as externally based EI programs or an Early Learning and Care program.

This means that ISS funding is currently only provided to mainstream childcare service providers. These service providers are not able to provide childcare services under a delivery model that maximises long-term outcomes for children with autism (see section 4.2.2). As has been previously discussed, the functional communication problems, social anxiety and behavioural challenges that are present in children with autism and the broad spectrum of the disorder mean that very specific service delivery programs are necessary to maximise long-term outcomes. This requires services to be provided through a specialised childcare setting, something that cannot be achieved in a mainstream facility.

The implication of the exclusion of specialised childcare service providers from the ISS is that organisations providing Early Learning and Care services to children with autism that are consistent with the Commonwealth Government's Best Practice guidelines cannot access funding under the program that is intended to facilitate the delivery of effective childcare services to children with disability. While this funding

can be accessed for a child with autism, it is only to the extent that they are attending a mainstream childcare program. This results in sub-optimal outcomes, with inappropriately skilled staff supporting children with disability in a mainstream childcare setting. It is also important to note that Best Practice service delivery programs include the flexibility necessary to facilitate the integration of children with autism with typically developing peers in mainstream childcare environments if the progress of the child indicates that it is appropriate.

The current scenario has resulted in parents of children with autism having to choose between the following methods of service delivery:

- a fully funded childcare service that is not consistent with the Government's Best Practice guidelines and does not optimise long-term outcomes for children with autism (and therefore does not represent an efficient and effective allocation of government funding); or
- a service that is consistent with the Government's Best Practice guidelines for which there is a significant gap between the cost of service provision and government funding provided.

By excluding organisations that are delivering Best Practice Early Learning and Care services to children with autism, the ISP is failing to facilitate the delivery of childcare services to children with additional needs that optimises long-term outcomes and quality of life, for the children, their parents, and the wider community.

### **7.3 Proposed funding approach**

As has been identified in section 5.3, the cost of providing Best Practice Early Learning and Care services to children with autism is estimated at \$43,000 per child per annum (acknowledging the proposal for State Governments to contribute \$3,000 per child per annum for site occupation costs), with funding to be provided over a two year period. This corresponds to an estimated range for the total annual cost of \$57.3 million to \$61.6 million.

To satisfy the objective of providing these services to all eligible children, regardless of social and economic circumstances, it is considered necessary for the full cost of the program to be funded by government. A key funding source that has been identified that could help achieve this goal that currently cannot be accessed is the ISS program.

As a result of their exclusion from accessing ISS funding, families seeking Early Learning and Care services for their children are limited to obtaining government support from the HCWA and childcare assistance packages (including the CCR, CCB and the carer allowance), part of which is means tested. As has been previously



identified, eligible children are entitled to a total of \$12,000 under the HCWA EI package. As the proposed Early Learning and Care program occurs over a two year period, this corresponds to \$6,000 per child per annum.<sup>35</sup>

The CCR enables families to access up to \$7,500 per child per annum to assist with meeting the cost of childcare services. Given the intense nature of the services provided under the proposed framework (i.e. the Best Practice guidelines), it is considered that this amount of funding would be available to assist in meeting the cost of providing Early Learning and Care services to children with autism on an annual basis (with the exception of low-income families, who would receive less than \$7,500 due to the greater amount of funding received under the CCB).

Families of children with autism are also potentially eligible for childcare funding under the income-tested CCB. Subject to their level of income, families with eligible children are entitled to between \$0 and \$7,066 per annum.<sup>36</sup> The amount of funding available from the CCB varies with family income, however it is recognised that it represents a significant contribution to meeting the total cost of the proposed Early Learning and Care program, particularly for low-income families. The carer allowance provides another source of funding for parents of children with autism, with approximately \$3,374 per annum available from this source.

Families seeking Best Practice Early Learning and Care services for their children are therefore currently eligible for between \$16,874 and \$23,940 in government funding per child per annum. This leaves an annual funding gap of between \$19,060 and \$26,126 per child (depending on family income levels).

It is proposed that this funding gap can be significantly reduced or eliminated (for low-income families) by allowing families to access the equivalent funding that is provided to childcare service providers under the ISS for their child to attend an Early Learning and Care program, that is, specialised childcare rather than mainstream childcare (\$21,047 per child per annum). There are two options available to government to facilitate the provision of this funding for Early Learning and Care services:

- refinement of the objectives of the ISP to remove the exclusion that currently applies to non-mainstream childcare service providers, including organisations providing Early Learning and Care services to children with autism; or

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<sup>35</sup> It is necessary to note that the HCWA package is scheduled to conclude in 2012 with no information currently available as to whether the funding assistance is to be extended.

<sup>36</sup> This range is based on the current CCB rate of \$3.68 per hour and an Early Learning and Care program that provides services for 40 hours per week, 48 weeks per year,

- establish a new funding program which enables families with children attending an accredited Early Learning and Care program to access equivalent funding assistance that is currently provided to childcare service providers under the ISS.

The advantage of the first option is the lower administrative burden associated with altering an existing funding program as opposed to establishing a new program.

The 2006 Parliamentary Inquiry into balancing work and family supports this proposal to provide ISS funding to Early Learning and Care service providers, with the inquiry recommending that:<sup>37</sup>

The Department of Families, Community Services and Indigenous Affairs make access to its funding programs more flexible, including the \$19,000 per child per annum under the Inclusion Support Scheme, so that community groups and businesses can establish child care centres that have expertise in the needs of children with a disability and allow the development of after school hours care and vacation care for special needs children.

As outlined above, the way the ISS program has been implemented impedes the achievement of this objective because the manner in which the funding is provided, that is, facilitating the employment of additional support staff in a mainstream childcare centre, will not result in effective outcomes for children with autism. Hence, at least for these children, these resources are not being optimally utilised.

Providing Early Learning and Care service providers with ISS-equivalent funding would significantly reduce or even eliminate (depending on the funding received by families under the CCB) the gap between the cost of delivering Best Practice Early Learning and Care services to children with autism and the level of funding provided. It is considered that any residual funding gap could be met by a combination of funding provided by other sources (mostly private contributions).

Table 4 provides a summary of the impact that providing ISS-equivalent funding to families of children with autism will have on the cost incurred by families at different income levels for the provision of Early Learning and Care services.

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<sup>37</sup> The Parliament of the Commonwealth of Australia (2006). Balancing Work and Family – Report on the inquiry into balancing work and family. House of Representatives – Standing Committee on Family and Human Services, p 285.

**Table 4 Breakdown of funding provided for the Early Learning and Care program**

Family income (CCB%)	Annual cost (\$) <sup>a</sup>	CCB (\$)	HCWA (\$)	CCR (\$)	Carer allowance (\$)	ISS-equivalent funding (\$)	Out-of-pocket costs (\$)
<\$37,000 (100%)	43,000	7,065.60	6,000	6,967.20	3,374.20	21,047	-
\$60,000 (76.45%)	43,000	5,401.65	6,000	7,500	3,374.20	21,047	-
\$80,000 (55.09%)	43,000	3,892.44	6,000	7,500	3,374.20	21,047	1,186.36
\$100,000 (33%)	43,000	2,331.65	6,000	7,500	3,374.20	21,047	2,747.15
>\$134,000 (0%)	43,000	0	6,000	7,500	3,374.20	21,047	5,078.80

<sup>a</sup> If State Governments were to provide \$3,000 per child per annum to meet site occupation costs as is proposed in this submission, the carer allowance could be used to otherwise alleviate the financial burdens imposed on families of children with autism.

Source: AEIOU.

In addition to showing that the proposed funding model will result in low-income families being provided with access to fully-funded Best Practice Early Learning and Care services, Table 4 shows that a significant proportion of the annual cost of the Early Learning and Care program could be met using existing funding sources.

The incremental annual cost of the program to government on a per child basis is estimated at \$21,047 (the ISS-equivalent funding) less the existing ISS funding that is provided to children that would be eligible under the proposed program. Based on the range of prevalence estimates used in section 5.3, this translates to a maximum additional funding requirement of between \$28 million and \$30.1 million per annum, less ISS funding that is currently provided to eligible children. AEIOU has indicated that based on discussions with mainstream childcare service providers, approximately 30% of ISS funding is provided to children with autism. Based on an estimate for total ISS expenditure of \$28.8 million, this equates to an additional \$8.6 million that could be redirected to meet the cost of the proposed Early Learning and Care program. This would reduce the additional funding associated with the program to \$19.4 million to \$21.5 million per annum.

The Commonwealth's contribution could be reduced by funding from the State Government. Generally this submission is proposing an income support measure which is the responsibility of the Commonwealth. However, the implementation of the program will require the development of buildings to operate the programs. Funding could be provided by State and Territory Governments to support the development and maintenance of facilities. The funding provision could include:

- the provision of funding to service providers to cover the \$3,000 per child per annum site occupation fees (i.e. rent) for specialised childcare centres (as previously discussed in section 5.3);
- the provision of assistance to individual service providers to assist in the construction of new Early Learning and Care centres. State Governments are in a

better position than the Federal Government to identify needs throughout the State and to evaluate funding proposals from service providers; and

- making decisions regarding the provision of Early Learning and Care services to eligible children in rural and remote communities.

## 8 Implementation issues

In administering any increase in government funding assistance it is necessary to consider the impacts of the increase in funding on the relevant markets. Failure to consider these impacts could potentially threaten the efficiency and effectiveness of the additional funding provided.

The impact on wage levels in the relevant labour markets (i.e. speech pathology and occupational therapy) is the most significant issue in relation to the additional funding proposed. This is discussed in the following sections, in addition to several other potential impacts.

### 8.1 Labour market issues

An indication of the labour market impacts that could potentially arise as a result of the provision of additional Early Learning and Care funding can be observed through the impact of the HCWA EI package. The provision of additional funding for services under this package has significantly impacted on the relevant labour markets, with the resulting expansion of demand causing a significant increase in the wage levels of speech pathologists and occupational therapists.

The magnitude of the increase in wage levels in these labour markets is largely attributable to the unresponsive nature of supply in the relevant labour markets. This is a result of the absence of an effective link between the level of demand for these services and the number of training placements made available in tertiary education institutions (i.e. there is no framework in place to ensure that shortages in supply result in the creation of additional placements in tertiary education institutions). The number of placements made available is determined by education funding allocations, which are typically formulated without reference to market conditions.

The significant increase in wage levels that have been observed in these labour markets have constrained the effectiveness of the HCWA EI package, as the higher cost of the services has restricted the extent to which the additional funding provided has facilitated the delivery of additional EI services to children with autism.

It is also necessary to note the impact that providing additional government funding can have on the relevant labour markets in terms of the wage differentials between service providers in different sectors. While the wage levels of service providers in the public and not for profit sectors remain unchanged, the additional demand in the private sector as a result of private organisations obtaining access to additional government funding results in the equilibrium wage levels in the private sector increasing significantly. There are equity concerns associated with this increased

differential in wage rates within the same labour markets in addition to concerns relating to the level of supply available for the public and not for profit sectors.

The impact of cost shocks caused by significant increases in wage levels due to a lack of capacity in the supply side of the relevant labour markets is also of concern in relation to the increase in the level of funding provided for Early Learning and Care services as is proposed in this submission. This will need to be addressed through the implementation of appropriate transitional arrangements, such as staged increases in the provision of funding coordinated with a program to facilitate the expansion of the supply side of the relevant labour markets.

## **8.2 Supply lags**

When implementing any increase in government funding it is important to consider the capacity of the supply side of the relevant market (i.e. the provision of Early Learning and Care services to children with autism). Based on a high-level assessment of the supply side of the market for Early Learning and Care services for children with autism it is considered that the market does not currently possess sufficient capacity to meet the increase in demand likely to result from the provision of the proposed funding.

This observation further stresses the importance of appropriate transitional arrangements being implemented, with staged funding increases over an initial implementation period combined with a program to expand capacity in the supply side of the market. Such a 'ramp-up' mechanism will, in addition to avoiding the scenario in which the level of funding made available results in demand for Best Practice EI services exceeding the capacity of the supply side of the market, also alleviate the labour cost pressures discussed in the previous section.

## **8.3 Implications for existing service users**

The proposal outlined in this submission involves increasing the level of funding available to facilitate the provision of Early Learning and Care services to children with autism. The implementation of this proposal will not result in any children with ASD that are currently receiving funding but are outside of the target group for the proposed increase in funding being disadvantaged (i.e. a reduction in the level of funding provided). This is due to the proposal only involving the redirection of existing funding that is currently provided to children that would be eligible for funding under the proposed Early Learning and Care program. This means that, for those children with ASD that do not satisfy the eligibility criteria under the proposal,

any funding currently provided under existing programs would continue to be provided.

The proposed program therefore involves the provision of Early Learning and Care services to those children for which the benefits of this form of service delivery have been established at no disadvantage to those children that are outside of the proposed program's target group.

## **8.4 Definition of government responsibilities**

As is discussed in section 6.1.2, it will be necessary for the responsibilities of the State and Federal Governments to be clearly defined as part of the proposed Early Learning and Care program. The appropriate role for State Governments is likely to relate to contributing site occupation fees of approximately \$3,000 per child per annum, identifying regional demand and supply imbalances, and providing funding assistance to service providers to correct the imbalances by facilitating the establishment of new Early Learning and Care centres.

State and Territory Governments will also need to address the issue of the provision of Early Learning and Care services to eligible children in rural and remote areas, in addition to establishing the necessary framework to enable multidisciplinary-based diagnostic assessments to be undertaken. The implementation of the necessary audit procedures to ensure that the integrity of the program is maintained will also be a responsibility of State and Territory Governments.



## 9 Conclusion

Early Learning and Care combines Best Practice EI with specialised childcare. Current funding arrangements are failing to facilitate the delivery of Early Learning and Care services to children with autism in a manner that satisfies the central objectives of efficiency and effectiveness. It is in this context that this submission proposes the inclusion of an Early Learning and Care program in the Australian Government's national scheme for the long-term care of people with disability. It is proposed that funding should be made available to allow for the provision of these services to all eligible children, regardless of social and economic circumstances.

While this submission has focused on children with autism (the most prevalent developmental disability in children) due to the strong evidence supporting the long-term benefits of intensive Early Learning and Care services for these children, it is proposed that the program could be expanded to include any disability for which there is strong evidence of the benefits of providing services under the proposed model.

The framework for the proposed increase in funding has been designed to satisfy the objective of facilitating the provision of Early Learning and Care services to children with autism in a manner that is consistent with the Federal Government's Best Practice guidelines, regardless of social and economic circumstances. This is not currently being achieved under the existing funding programs, largely as a result of the poor targeting of the ISS.

It is considered that the revised framework proposed in this submission will remove these shortcomings. While there is a significant cost associated with the proposed program (estimated at \$43,000 per child per annum), the total funding burden on the Federal Government would be reduced through the redirection of funding currently provided to children that would be eligible under the proposed program through existing funding, including the CCR, the CCB, the carer allowance and the ISS. It is estimated that the incremental cost of the proposed program to government would be approximately \$20.5 million per annum (based on a range of \$19.4 million to \$21.5 million).

In implementing the Early Learning and Care program as is proposed in this submission, the Federal Government would need to have regard to the following issues:

- the break-down of responsibilities between the State and Federal Governments and the forward-looking role of State Governments in providing funding for the delivery of Early Learning and Care services;



- the necessary governance and administration mechanisms to be implemented to ensure the program achieves its stated objectives and maintains consistency with the principles of efficiency and effectiveness; and
- transitional arrangements necessary to facilitate the implementation of the additional funding, including staged increases in the level of funding to prevent wage cost pressures and to ensure that the supply side of the market expands sufficiently to meet demand for Early Learning and Care services.