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Reviewing the evidence on the effectiveness of early childhood intervention

Report to the Department of Families, Housing, Community Services and Indigenous Affairs

30 September 2011



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Disclaimer

Inherent Limitations

This report has been prepared as outlined in the Project objectives section. The services provided in connection with this engagement comprise an advisory engagement, which is not subject to assurance or other standards issued by the Australian Auditing and Assurance Standards Board and consequently no opinions or conclusions intended to convey assurance have been expressed.

No warranty of completeness, accuracy or reliability is given in relation to the statements and representations made by, and the information and documentation provided by the Department of Families, Housing, Community Services and Indigenous Affairs personnel and others consulted as part of the process.

KPMG have indicated within this report the sources of the information provided. KPMG has not sought to independently verify those sources unless otherwise noted within the report.

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The findings in this report have been formed on the above basis.

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Glossary

ASD — Autism Spectrum Disorder

CEA — Cost Effectiveness Analysis

ECI — Early Childhood Intervention

FaHCSIA — Commonwealth Government of Families, Housing, Community Services and Indigenous Affairs

ICF-CY — International Classification of Functioning, Disability and Health for Children and Youth

HCWA — Helping Children with Autism package

HELP — Hawaii Early Learning Profile

NDA — National Disability Agreement

NDIS — National Disability Insurance Scheme

OECD — Organisation for Economic Cooperation and Development

SDAC — Survey of Disability and Carers

Executive summary

About this project

KPMG was engaged by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) to review and document the evidence base on the effectiveness of early childhood intervention (ECI) for children with a developmental disability. There is a significant body of evidence on the effectiveness of ECI for children with specific types of disability or underlying condition (such as autism spectrum disorder, cerebral palsy), and the focus of this project has been to review the evidence from a broader perspective – that is, the effectiveness of ECI for children with a developmental disability or developmental delay regardless of underlying cause or condition.

This report describes the outputs of KPMG's work for FaHCSIA in responding to the following questions:

- Is early intervention generally associated with improved outcomes for childhood developmental disabilities?
- Does early intervention assist children with developmental disabilities in making a successful transition to school?
- Does early intervention have an association, either direct or indirect, with social and workforce participation later in life?
- What current research is available comparing the use of diagnostic or functional thresholds to determine eligibility for early intervention, and what are the design features of a tool that could determine eligibility for assistance?
- Based on an examination of the estimated numbers of Australian children with a developmental delay, what would be the cost implications – both short term costs and longer term benefits - of expanding current Australian Government funding for early intervention services for such children?

Project context

Early childhood intervention has been demonstrated to be effective in improving outcomes for children, families and communities. Three broad rationales are often given for emphasising ECI in policy making:

- a *child development* rationale that emphasises ECI in helping society fully develop and utilise the skills of all children
- a *economic* rationale, that says that ECI provides a sound return on investment
- an *ethical* rationale that argues that all children should be able to reach their potential.

Early childhood intervention is delivered to both a broad cohort of children and children with well-identified, specialist intervention needs. Interventions are also designed to support families to intervene effectively in their children's development.

Both the Australian Government and state and territory governments support children with a developmental disability or delay and their families through early childhood intervention. The Australian Government investment in ECI relates largely to:

- the Helping Children with Autism (HCWA) package and
- the Better Start initiative

While aspects of this report will have broad relevance for a range of ECI services, the focus of this report is on the Better Start initiative.

As a key support to children with a developmental disability, there are strong links between the ECI and adult disability service systems across Australia. As a result, reforms to ECI must be considered in the context of changes to disability policy more broadly. Of particular relevance is the Australian Government's in-principle support for the establishment of a National Disability Insurance Scheme (NDIS). In developing the NDIS, further work is required to:

- develop assessment tools to determine eligibility for support
- develop service and quality standards

- develop a national pricing structure
- build the capacity of the disability sector
- build workforce capacity.

The NDIS represents a significant opportunity to refine policy and programs relating to support for children with a disability and their families.

Literature — responding to four key questions

Is early intervention generally associated with improved outcomes for childhood developmental disabilities?

Early childhood intervention is associated with improved outcomes for children with a broad range of vulnerabilities — including disability. However, the evidence for the broad social and developmental impacts of ECI is stronger for a broad group of children than for children with a developmental disability specifically. This notwithstanding, there is sufficient evidence to be able to suggest that a range of interventions improve outcomes for children with a developmental disability, particularly those that support both children and their families in children's 'natural environments'.

Does early intervention assist children with developmental disabilities in making a successful transition to school?

While there is some evidence to suggest that generalist programs support children with a range of vulnerabilities to successfully transition to school, there is less evidence relating specifically to children with developmental disabilities. However, a number of interventions aimed specifically at children with a developmental disability improve a range of learning outcomes, from which it is possible to infer improvements in school transitions. Further, ECI is often aimed at improving overall family functioning to support children's broader development. As such, while ECI may improve educational outcomes, these outcomes may not be the primary focus of interventions.

Does early intervention have an association, either direct or indirect, with social and workforce participation later in life?

Both generalist and specialist interventions report success in improving social and workforce participation outcomes for children later in life. For example, and as 3 – literature review outlines, large, universally-based program such as the Perry Preschool program and smaller, more targeted programs that work with children with specific needs, such as those supported by the First Voice

group of services, report improvements in a variety of areas relating to social and workforce participation. (See 3 – *literature review* for more information).

Further, evidence also exists for the improvements in social and workforce participation of families of children with a developmental disability.

What current research is available comparing the use of diagnostic or functional thresholds to determine eligibility for early intervention, and what are the design features of a tool that could determine eligibility for assistance?

Literature indicates that functional assessments that consider both children's strengths and needs, and that consider the broader family context, are preferable to diagnostically-based assessment approaches.

A range of assessment tools exist to facilitate functional assessments for the cohort served by Better Start. However, these tools would require modification and customisation for implementation in an Australian context.

Effectiveness analysis

A key aim for this study is to examine the costs and benefits of expanding current Australian Government funding for early intervention services for children with a disability or developmental delay. The lack of detailed data addressing the potential benefits of different early intervention programs targeted at children with a disability or developmental delay meant that it was not possible to establish (within a CEA framework) robust counterfactuals to enable an assessment of the relative merits of different intervention approaches.

Instead, KPMG has:

- examined the range of benefits that have been shown to accrue to early intervention generally
- examined the extent to which certain conditions and recognised developmental delays exhibit symptoms that are consistent with the benefits that have been shown to accrue to early intervention – i.e. intellectual development, social development and emotional development
- estimated the potential number of children with these relevant conditions that may qualify for additional assistance to determine the potential cost to the Australian Government of extending the Better Start funding to these children, and

- considered the potential benefits that may accrue to children with the identified conditions, based on the presence in these children of particular developmental delays to which early intervention have been shown to improve outcomes.

After applying this framework to a range of potential conditions that could be considered for inclusion, the assessment revealed that eight chromosomal conditions and Microcephaly are likely to cost the least, in terms of their incremental impact on Better Start (with the additional costs estimated to be in the order of \$3 to \$3.5 million per annum). Further, children with these conditions are also most likely to benefit from early intervention in terms of their intellectual development, social development and emotional development, as compared to other conditions that could be considered for inclusion.

Bringing it all together

To draw together the findings of this report, KPMG has considered:

- Qualitative evidence from a review of research literature
- Quantitative evidence on the effectiveness of early childhood intervention programs
- The views of experts in the early childhood intervention field.

KPMG's conclusions relate to three broad areas.

Assessment

Assessment provides a mechanism by which child and family needs are identified and the possible range of service responses are considered. As such, assessment is central to the Australian Government's early childhood intervention programs.

However, both research literature and stakeholder contributions emphasised that functional assessment processes – which consider the needs and strengths of children and families in determining support options – allow services to be more appropriately targeted to individual child and family circumstances than diagnostically-based assessment approaches.

Access and choice

Stakeholders consulted for this project noted that a tension exists between improving the choice and intensity of ECI supports available to eligible families and broadening eligibility criteria to allow greater access to ECI supports for a larger number of children. In effect, the current approach to assessment reflects an understanding of ECI as discrete services, rather than as supports that build families' skills in managing their needs.

Coordination and streamlining

Stakeholders also observed that the current Australian Government approach to supporting children under the HCWA package and Better Start initiative can add to the complexity experienced by eligible families. In particular, the role of parents in identifying and accessing appropriate supports can significantly contribute to the challenges families face in meeting their and their children's needs. Opportunities exist to streamline the parallel ECI processes in place across the state and territory and Australian Government systems.

Considering these issues in the current policy context

Many of the issues raised in this report are also issues that will be considered during the development of the NDIS. In particular:

- developing appropriate functional assessment approaches
- enhancing the coordination of support for families at a local level.

Consequently, it is desirable that reforms to Australian Government early childhood intervention initiatives should contribute to (or be reviewed in light of) the developmental work for the NDIS.

Conditional options

KPMG has identified three broad approaches for refining the Australian Government's approach to supporting children with a developmental disability.

Conditional option 1 — Incremental refinement of existing Australian Government support for early childhood intervention

Conditional option 1 (below) proposes incremental refinements of the Australian Government's existing approach, building on both the literature review and the economic analysis of the effectiveness of specific programs. The Australian Government should consider conditional option 1 if it wishes to

retain the existing infrastructure for determining eligibility under Better Start, while expanding the range of conditions on which eligibility is determined.

Conditional option 1

Conditional option 1 — Incremental refinement of existing Australian Government support for early childhood intervention

This option would incrementally refine the eligibility criteria for Better Start by adding a limited number of additional conditions for which there is evidence of the effectiveness of interventions. As discussed in section 5 – *implications for government policy*, taking the program costs and potential benefits into account, it is considered that the conditions most suitable for inclusion in the Better Start program are Chromosomal conditions (including Prada Willi Syndrome; Williams Syndrome; Angelman Syndrome; Kabuki Make Up Syndrome; Simth Magenis Syndrome; Cri de Chat syndrome; CHARGE syndrome; and Cornelia de Lange syndrome) and Microcephaly.

Chromosomal conditions and Microcephaly are likely to cost the least, in terms of their incremental impact on Better Start (with the additional costs estimated to be in the order of \$3 to \$3.5 million per annum). Further, children with these conditions are also most likely to benefit from early intervention in terms of their intellectual development, social development and emotional development.

Expanding the Better Start eligibility criteria to include these conditions would increase the number of children and families able to access evidence-based early childhood intervention supports.

Source: KPMG analysis

Conditional option 2 – Building strong linkages for children and families across early childhood services

Conditional option 2 (below) describes work to streamline the support provided by the Australian Government and state and territory governments for children with a disability and their families. The Australian Government should consider conditional option 2 if it wishes to respond to the evidence in the research literature on the value of streamlining support for children with a disability and their families through establishing more integrated, coherent pathways into ECI across the spectrum of early childhood services available through

providers funded by both the Australian Government and state and territory governments.

Conditional option 2

Conditional option 2 — Building stronger linkages for children and families across early childhood services

As outlined earlier in this chapter, overlaps in the roles of the Australian and state and territory governments have the potential to add complexity to the lives of children and families accessing ECI. An opportunity exists for the Australian Government and the state and territory governments to contribute to improving the overall accessibility and coordination of the ECI service system.

Reflecting this, conditional option 2 would see the Australian Government working closely with state and territory governments to link families more closely with appropriate services in both universal and specialist service settings. Under this option, the Australian Government would – with the cooperation of state and territory agencies responsible for ECI services – improve the understanding of and coordination between Better Start and other ECI services for families. In particular, work should be undertaken to specifically identify opportunities for Better Start to complement existing state and territory ECI systems.

Both the Australian Government and the various state and territory governments recognise the potential for better alignment and integration of ECI service systems. To this end, FaHCSIA has recently had some preliminary discussions with the Victorian Government Department of Education and Early Childhood Development about jointly undertaking work to develop principles and strategies that would ensure that the Better Start initiative meets its intended aim of complementing the Victorian Government's role in its ECI service system. This work could be progressed and expanded through the Better Start State and Territory Working Group.

Source: KPMG analysis

Conditional option 3 — Working with the proposed NDIS to substantively reform early childhood intervention nationally

Conditional option 3 (below) involves more extensive reform of early intervention nationally in the context of the broader development of a National Disability Insurance Scheme. The Australian Government should consider conditional option 3 if it wishes to leverage the possible introduction of an NDIS to significantly reform its support for ECI.

Conditional option 3

Conditional option 3 — Working with the proposed NDIS to substantively reform early childhood intervention nationally

Under this option, the Australian Government would – in the event of an NDIS being established – work with state and territory governments through the Council of Australian Governments and the taskforce charged with implementing the NDIS to identify early childhood intervention as a priority for the NDIS’s early implementation. There is a strong logic in linking current early childhood intervention supports to the NDIS, since such links would significantly streamline families’ experiences of interventions – particularly for those families accessing supports from both the Commonwealth and state and territory systems.

Linking with the NDIS would allow the Australian Government to leverage the likely investments in establishing the NDIS infrastructure — including a nationally-consistent assessment methodology and framework for coordinating support at the local level — to refine the current approaches of the HCWA package and Better Start initiative.

There are also substantial linkages between ECI and other services targeted to children. An opportunity exists for ECI to leverage off those linkages, particularly through the Council of Australian Governments’ efforts on the *National Partnership Agreement on Early Childhood Education*, the *National Partnership Agreement on the National Quality Agenda for Early Childhood Education and Care* and the *National Partnership Agreement on Indigenous Early Childhood Development*.

Source: KPMG analysis

1 About this report

This report describes KPMG's work for FaHCSIA in responding to the following questions:

- Is early intervention generally associated with improved outcomes for childhood developmental disabilities?
- Does early intervention assist children with developmental disabilities in making a successful transition to school?
- Does early intervention have an association, either direct or indirect, with social and workforce participation later in life?
- What current research is available comparing the use of diagnostic or functional thresholds to determine eligibility for early intervention, and what are the design features of a tool that could determine eligibility for assistance?
- Based on an examination of the estimated numbers of Australian children with a developmental delay, what would be the cost implications – both short term costs and longer term benefits - of expanding current Australian Government funding for early intervention services for such children?

Project objectives

KPMG was engaged by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) to review and document the evidence base on the effectiveness of early childhood intervention (ECI) for children with a developmental disability. There is a significant body of evidence on the effectiveness of ECI for children with specific types of disability or underlying condition (such as autism spectrum disorder, cerebral palsy), and the focus of this project has been to review the evidence from a broader perspective – that is, the effectiveness of ECI for children with a developmental disability or developmental delay regardless of underlying cause or condition. Given recent trends in supporting children with a developmental disability or developmental delay and their families in mainstream settings as well as specific ECI settings, the review of evidence has encompassed both mainstream and specialist settings.

Following on from this research, KPMG undertook analysis to describe the broad cost implications of expanding Australian Government ECI funding to enable more children with a developmental disability to benefit from ECI services. Building on this analysis, KPMG also extrapolated from existing research to describe the likely longer-term benefits of additional investment.

In undertaking this work, KPMG has focused on the following key questions:

- Is early intervention generally associated with improved outcomes for childhood developmental disabilities?
- Does early intervention assist children with developmental disabilities in making a successful transition to school?
- Does early intervention have an association, either direct or indirect, with social and workforce participation later in life?
- What current research is available comparing the use of diagnostic or functional thresholds to determine eligibility for early intervention, and what are the design features of a tool that could determine eligibility for assistance?

- Based on an examination of the estimated numbers of Australian children with a developmental delay, what would be the cost implications – both short term costs and longer term benefits - of expanding current Australian Government funding for early intervention services for such children?

This report documents KPMG's findings. It is structured as follows:

2 — Project context describes the relevant context for the project, including definitions of ECI, an overview of why ECI is important, a discussion of the ECI target group, and a snapshot of the current policy context, including the proposed introduction of a National Disability Insurance scheme.

3 — Literature review — responding to four key questions details the results of KPMG's review of the research literature relating to ECI.

4 — Cost effectiveness — the broad issues considers the appropriate frameworks for conducting an economic assessment of ECI in children with a disability or development delay.

5 — Applying principles of cost effectiveness to Government policy applies the framework established in the prior section to potential conditions for inclusion in the Better Start program.

6 — Bringing it all together draws together the findings of KPMG's literature review and cost analysis. It also describes the findings of KPMG's consultations with key stakeholders. These consultations were an important element in developing options for FaHCSIA, consistent with both the research literature and cost analysis.

2 Project context

This chapter describes the relevant context relating to ECI in Australia. It includes:

- definitions of ECI
- why ECI is important
- who ECI is designed to support and
- the national policy context, including the possible establishment of a National Disability Insurance Scheme

What is Early Childhood Intervention?

Early childhood intervention (ECI) comprises a range of activities aimed at improving a broad range of outcomes for children and families. As such, arriving at a definition that adequately represents the full range of these activities is not straightforward. In its final report on the National Disability Insurance scheme, the Productivity Commission noted that:

It became evident to the Commission from participants' comments and from government policy documents and reports that 'early intervention' is not easy to define precisely in relation to disability care and support.¹

At one level, early intervention refers to the strategies, practices and therapies designed to help children with a disability or developmental delay to participate as fully as they are able in social, educational and economic life.

At a higher level, early intervention can be conceived of in two ways. First, early intervention can be said to describe a service system that mobilises to support children and families with emerging needs relating to a child's disability or developmental delay. This service-oriented conception of ECI is based on Shonkoff and Meisels' description of early childhood intervention in the *Handbook of Early Childhood Intervention*² and is one of the most prominent:

Early childhood intervention consists of multidisciplinary services provided to children from birth to 5 years of age to promote child health and well-being, enhance emerging competencies, minimize developmental delays, remediate existing or emerging disabilities, prevent functional deterioration, and promote adaptive parenting and overall family functioning. These goals are accomplished by providing individualized developmental, educational, and therapeutic services for children in conjunction with mutually planned support for their families.

However, early childhood intervention can also be conceived as a process, where intervention modifies the natural environments in which children develop — that is, the environments that children inhabit and experience in

¹ Productivity Commission 2011 *Disability Care and Support*, Productivity Commission Report no. 54, Productivity Commission, Canberra, p. 11.4.

² Shonkoff & Meisels 2000 *The Handbook of Early Childhood Intervention* 2nd Edition, Cambridge University Press, Cambridge, UK.

their every day lives — to improve the functioning of both children and their families. Consistent with this approach, Dunst and Trivette have defined early intervention:

[A]s the provision or mobilisation of supports and resources to families of young children from informal and formal social network members that either directly or indirectly influence and improve parent, family, and child behavior and functioning. The experiences, opportunities, advice, guidance, and so forth afforded families by social network members are conceptualized broadly as different types of interventions contributing to improved functioning.³

The Dunst and Trivette conception of early intervention promotes a much greater sense of active co-construction of children and families' interventions, and situates families at the heart of decision-making regarding their support needs.

However, the distinctions between these definitions are crucial, and are at the heart of many of the issues outlined throughout this report, for reasons that the Centre for Community Child Health has articulated:

If early childhood intervention is defined in terms of providing children with experiences and opportunities that promote competencies that enable them to participate meaningfully in home and community environments, then the focus will be on ensuring that families and other carers are able to provide children with such experiences and opportunities. In other words, the aim will be to ensure that the child's everyday learning environments are optimal.

If early childhood intervention is defined in terms of providing children and families with services, then the emphasis will be on the nature and quality of those services, and on changing the child's behaviour directly rather than on changing the child's learning environments.⁴

This distinction between the focus on outcomes for children and families and on the services that children can receive resonates strongly in the literature reviewed as part of this project. There is an extensive literature focusing on the outcomes that a range of children can achieve with the support of quality

³ Dunst, C & Trivette, C 2009 'Capacity-building family-systems intervention practices', *Journal of Family Social Work*, 12 (2), 119–143.

⁴ Centre for Community Child Health 2010 *Early childhood intervention services — Revised literature review*, report to the Victorian Government Department of Education and Early Childhood Development, Melbourne, December, p. 36.

early childhood interventions. However, this *generalist* literature tends to focus on general interventions that target a range of children, including those with developmental disabilities or delay. Alternatively, there is a different, broader literature that describes the impact of specific interventions on children with specific disabilities. However, this *specialist* literature focuses on the services, or interventions, that are provided to children, and is less descriptive about the broader outcomes that those children achieve.

In addition to describing the outcomes or process involved in intervening in the life of a child with a disability, other definitions of early childhood intervention describe the rights of children to develop and grow. Under the United Nations Convention on the Rights of the Child:

*all children have the right to participate fully in and to benefit from educational experiences and play a full part in society.*⁵

However, for many children with a disability or developmental delay, acting on this right is not straightforward — or in some cases possible. Disability and developmental delay can become a barrier preventing children from participating in education, and the effects of non-participation in education can stay with children throughout their lives.⁶

In addition to defining early childhood intervention by virtue of what it does, it is possible to describe early intervention in terms of what it achieves — its intended outcomes. Such an outcomes-based conception of early intervention is no less complex than the service-based or human rights based approaches outlined above, and incorporates the thinking of a number of key early intervention theorists.

Carl Dunst has described two key objectives of early intervention. First, he describes the outcomes of early intervention for children as:

⁵ United Nations 1985 International Convention on the Rights of the Child, United Nations High Commissioner for Human Rights, Geneva. Available at <http://www2.ohchr.org/english/law/pdf/crc.pdf>.

⁶ Cuskelly, M & Hayes, A 2004 'Disability, characteristics, contexts and consequences', in Bowes (ed.) *Children, Families and Communities: Contexts and Consequences (2nd ed.)* Oxford University Press, Melbourne.

*Strengthen[ing] children's self-initiated and self-directed learning and development so as to promote their acquisition of functional behavioural competencies.*⁷

However, Dunst also identifies a second outcome of early intervention that emphasises the impact of interventions on families, noting that an objective of early intervention is to:

*strengthen parents' confidence and competence in providing their children with the experiences and opportunities that will promote their children's learning and development.*⁸

By defining the objectives of early intervention in this way, Dunst explicitly recognises the importance of acknowledging that children's needs must be considered in the context of their environments — of which families are a significant part.

While, as this section has observed, a range of definitions exist for early childhood intervention, throughout these alternative definitions — and throughout this report — there is a common understanding of early childhood intervention as responding to an identified need of a child with a disability and their family. Thinking about early childhood intervention in this way recognises the role of services and supports in helping children and families achieve a given objective, while at the same time understanding ECI as a process (and a journey) involving children, families and their formal and informal support networks. Importantly, the focus of ECI is on children in the context of their family. This focus influences how ECI is designed, from both a system perspective and from the perspective of individual children and families.

⁷ Dunst C 2007 Early intervention for infants and toddlers with developmental disabilities. In S.L. Odom, R.H. Horner, M.E. Snell and J. Blacher, J. (eds.), *Handbook of Developmental Disabilities*, Guilford Press New York.

⁸ Ibid.

Early childhood intervention has been demonstrated to be effective in improving outcomes for children, families and communities. Consequently, three broad rationales are often given for emphasising ECI in policy making:

- a child development rationale that emphasises ECI in helping society fully develop and utilise the skills of all children
- an economic rationale, that says that ECI provides a sound return on investment
- an ethical rationale that argues that all children should be able to reach their potential.

Why is early childhood intervention important?

As has been observed, early interventions help children to participate successfully in a fuller range of personal, social, educational and community activities during their early childhood years and in the future. Early interventions also support families to provide optimal environments for their children and to engage with others in the community who can provide informal and formal support.⁹ As such, effective early interventions, as the UK Government review of early intervention has acknowledged, can have a profound positive impact on individual children, families and the broader community:

Early Intervention enables every baby, child and young person to acquire the social and emotional foundations upon which our success as human beings depends. Most parents give this to their children, and often by instinct and common sense alone, but all of our children deserve nothing less. A child who is rounded, capable and sociable has a great chance in life. Those denied these qualities have a bad start and few of them recover. During their lifetimes they can impose heavy penalties on themselves and generate major costs, financial and social, for their families, local communities and the national economy.¹⁰

The Centre for Community Child Health has described a flow of logic that forms a key rationale for effective early intervention, as described in the box below:¹¹

⁹ Early Childhood Outcomes Center 2005 *Family and Child Outcomes for Early Intervention and Early Childhood Special Education*, Early Childhood Outcomes Center, California, April. Available at: http://www.fpg.unc.edu/~eco/pdfs/eco_outcomes_

¹⁰ Allen 2011 *Early Intervention — The Next Steps*, UK Commission on Early Intervention, London, March, p. 3.

¹¹ From Centre for Community Child Health 2010, Literature Review of Early Childhood Intervention Services, for Victorian Government Department of Education and Early Childhood Development, Melbourne, November, p. 13.

Exhibit 1

The logic of early childhood intervention

- Children develop through their relationships with the important people in their lives
- Sensitive and responsive care giving is a requirement for the healthy neurophysiological, physical and psychological development of a child.
- Relationships change brains neurologically and neurochemically, and these changes may be for the better or for the worse
- The attachments that children form with parents and caregivers create the central foundation from which the mind develops
- Skills develop cumulatively, so that those acquired early form the basis for later skill development (which is one of the reasons why behaviour and functioning at one point in time is predictive of later behaviour and functioning)
- But behaviour and functioning at any point in time are also strongly influenced by the immediate social and physical environment, regardless of earlier levels of behaviour and functioning
- Children's ongoing learning is a product of the interaction between learnings and patterns of behaviour arising from earlier environments and experiences, and the child's adaptation to the current environment
- Early behaviour and functioning are predictive of later behaviour and functioning to the extent that children's environments remain unchanged
- Changing children's environments is therefore critical for children's ongoing learning and development
- Children's ongoing learning depends upon having repeated opportunities to practice developmentally appropriate skills in everyday situations with support ('scaffolding') from attuned and responsive caregivers
- Children are active participants in their own development, creating effects on others and their environment by the way they initiate and respond. The effects are cumulative and bi-directional, sequentially impacting interactions and learning for all partners.

Source: Centre for Community Child Health 2010 Early childhood intervention services — Revised literature review , report to the Victorian Government Department of Education and Early Childhood Development, Melbourne, December.

While early intervention can be seen through the lenses of both human rights and ethics, government policy regarding early intervention in Australia has tended to focus on two principles that have been well-described in the research literature.¹²

¹² Centre for Community Child Health 2010 *Early childhood intervention services — Revised literature review* , report to the Victorian Government Department of Education and Early Childhood Development, Melbourne, December, p. 36

First, effective early intervention can promote economic benefits that extend far beyond individual children and families. In particular, this principle builds on the broader early childhood literature that emphasises the importance of investing in the early years to promote healthy children's development and to reduce the cost of interventions and other remediation efforts later in life. This is supported by work from Cunha and Heckman,¹³ Heckman¹⁴, Shonkoff and Phillips¹⁵ and Schweinhart¹⁶ that suggests that investments made in services provided to children in the early years of life, provide very significant benefits over a life time, since they reduce the need for governments to invest in more costly remediation and other interventions later in life. The UK Government's review of early intervention articulates this economic rationale for early intervention well:

Early Intervention is an approach which offers [...] a real opportunity to make lasting improvements in the lives of our children, to forestall many persistent social problems and end their transmission from one generation to the next, and to make long-term savings in public spending. It covers a range of tried and tested policies for the first three years of children's lives to give them the essential social and emotional security they need for the rest of their lives. It also includes a range of well-established policies for when they are older which leave children ready to face the challenges of each stage of childhood and of passage into adulthood — especially the challenge of becoming good parents to their own children.¹⁷

Second, early intervention is consistent with a well-developed understanding of children's development that emphasises the importance of the early years in promoting ongoing learning. There is a strong body of work, led by Shonkoff and Phillips¹⁸, Perry¹⁹ and McCain and Mustard²⁰, that describes the

¹³ Cunha, F & Heckman, J 2010 *Investing in Our Young People*, NBER Working Paper Series, Vol. w16201, National Bureau of Economic Research Cambridge, Massachusetts. Available at: <http://ssrn.com/abstract=1641577>.

¹⁴ Heckman, J 2004 'Invest in the very young' In Tremblay, Barr & De V Peters (eds.) *Encyclopedia on Early Childhood Development*, Centre of Excellence for Early Childhood Development, Montreal. Available at: <http://www.excellenceearlychildhood.ca/documents/HeckmanANG.pdf>.

¹⁵ Shonkoff, J. & Phillips, D. (eds.) 2000. *From Neurons to Neighborhoods: The Science of Early Childhood Development*, National Academy Press. Washington, DC.

¹⁶ Schweinhart, L 2004 *The High/Scope Perry Preschool Study Through Age 40: Summary, Conclusions and Frequently Asked Questions*, High/Scope Press, Ypsilanti.

¹⁷ Allen 2011 *Early Intervention — The Next Steps*, UK Commission on Early Intervention, London, March, p. vii.

¹⁸ Shonkoff, J. & Phillips, D. (eds.) 2000. *From Neurons to Neighborhoods: The Science of Early Childhood Development*, National Academy Press. Washington, DC.

importance of the early years in promoting healthy brain development. This literature builds on the scientific understanding of brain development, and observes that environments that do not promote healthy development have a cumulative and ongoing negative impact on a range of social, economic and learning outcomes over children's life course. This body of work emphasises that early interventions are a more effective means of improving children's outcomes than later remediation.

As discussed, however, early intervention also touches on profound issues relating to ethics and human rights. In this reading, early intervention represents an opportunity – and in some descriptions, an obligation – for society to support those who are most vulnerable. The report of the Perry Preschool program (described in 3 – literature review, below), concludes that:

Every child needs a good early childhood education. That's an ethical principle that transcends what the data say.²¹

Early childhood intervention is delivered to both a broad cohort of children and children with well-identified, specialist intervention needs. Interventions are also designed to support families to intervene effectively in their children's development.

Who is early intervention designed to support?

The economic and developmental rationales for early intervention described above imply that intervention responds to a defined need or mitigates an identified vulnerability. However, early interventions respond to a wide range of needs and a broad scope of vulnerabilities.

For example, much of the literature supporting the economic rationale for early intervention is based on programs that respond to social and economic needs. The Perry Preschool project, the Abecedarian project and the EPPE study (described in 3 – literature review, below) highlight the outcomes that can be achieved by providing high quality preschool programs to children who have been identified as being at risk of becoming developmentally vulnerable.

Early intervention in Australia, however, has generally been conceived more narrowly, in terms of the range of responses (that is, services) that are made available to children with a disability or developmental delay and their families. In this understanding, early intervention responds in well-defined ways to

¹⁹ Perry B 2002 'Childhood experience and the expression of genetic potential: what childhood neglect tells us about nature and nurture', in *Brain and Mind*, 3: 79–100.

²⁰ McCain, M & Mustard, F 1999 *Reversing the Real Brain Drain, Early Years Study Final Report*, Ontario Children's Secretariat Toronto.

²¹ Schweinhart, L 2004 *The High/Scope Perry Preschool Study Through Age 40: Summary, Conclusions and Frequently Asked Questions*, High/Scope Press, Ypsilanti.

children and families with well-defined needs. However, even this more limited understanding of early intervention can be misleading, due to the difficulty of identifying disability or developmental delay in children — particularly young children — and to the evolving understanding of disability itself.

The World Health Organisation has observed that the common conception of disability has been changing over recent decades, from a *deficit*, or *medical* model, to a *social* or *relative* model.²² The traditional *deficit* model saw disability as a liability, for which treatment was required. An emerging *social* perspective sees disability as socially constructed, in that people with a disability do not conform to social norms relating to mobility, communication or behaviour, and are therefore marginalised as a result.²³

The more recent World Health Organisation definition of disability is one of the most common and influential in relation to early intervention, and reflects a *social* model of disability.²⁴ The World Health Organisation definition adopts the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY). This classification describes not only physical or activity limitations, but also restrictions on children and young people's participation and the environments they inhabit.²⁵

While early intervention responds to children with a disability or developmental delay, interventions are also designed to support the families of children with a disability or developmental delay. The environments in which children live — including the family environment — influence their development.²⁶ Family functioning powerfully impacts on children's growth, so that where family functioning declines, children with a disability can find it more difficult to adapt and develop.

²² World Health Organisation 2002 *Towards a Common Language for Functioning, Disability and Health: The International Classification of Functioning, Disability and Health*, Geneva, Switzerland: World Health Organisation. Available at <http://www.who.int/classifications/icf/site/beginners/bg.pdf>.

²³ Centre for Community Child Health 2010 *Early childhood intervention services — Revised literature review*, report to the Victorian Government Department of Education and Early Childhood Development, Melbourne, December.

²⁴ World Health Organisation 2007 *International Classification of Functioning, Disability and Health - Children and Youth Version*, Geneva, Switzerland: World Health Organisation.

²⁵ Ibid.

²⁶ Bailey D 2007 'Introduction: Family adaptation to intellectual and developmental disabilities' in *Mental Retardation and Developmental Disabilities Research Reviews*, 13 (4), 291-292.

This notwithstanding, this report considers both interventions that respond to children's needs in a broad sense, as well as those that respond to the needs of children and families with specific needs relating to a disability or developmental delay.

Both the Australian Government and state and territory governments support children with a developmental disability or delay and their families through early childhood intervention.

The Australian Government investment in ECI relates largely through:

- the Helping Children with Autism package and
- the Better Start initiative

While aspects of this report will have broad relevance for a range of ECI services, the focus of this report is on the Better Start initiative.

Early intervention in Australia

Under the Australian Constitution, state and territory governments are responsible for the provision of early intervention services. In addition, the Australian Government has in recent years implemented two programs that provide targeted support to children with identified disabilities.

Children with a disability or developmental delay aged 0 to 4 years have the same needs as other children, and may have a range of additional needs to support and promote their development and enable them to participate in activities and settings with other children.

A number of services for young children with a disability or developmental delay have an early intervention and development focus, recognising that intervening early in a child's life and in crucial stages of a child's development can lead to better outcomes for a child — both in terms of their development and functional capacity. These services may be 'specialist' in nature and provided only for children with a developmental disability or developmental delay (such as supported playgroups, specific therapies, building family capacity), or provided in mainstream early childhood settings. There has been a definite move nationally and internationally to supporting children in this cohort group in mainstream settings, which allows children with a disability or developmental delay to participate with other children and to develop and learn through everyday settings and activities in the same way as other children. Further, there has been significant effort in recent years to ensure that mainstream services are inclusive of children with a disability or developmental delay, and that support is available for children with a disability or developmental delay to access or participate in these mainstream settings.

The Helping Children with Autism Package and Better Start initiative

Under the National Disability Agreement (NDA), the States and Territories generally have responsibility for the provision of specialist disability services to

young children. However, FaHCSIA administers two key initiatives targeted at children with a disability or developmental delay:

- **Helping Children with Autism (HCWA) Package** — aims to improve the education outcomes of children with autism spectrum disorders (ASD). The Package comprises a range of measures including:
 - An Autism Advisory Service, which provides advice, information and support immediately following diagnosis.
 - Early intervention assistance funding packages, which provide funding of up to \$12,000 (a maximum of \$6,000 per financial year) for early intervention services provided by registered providers
 - PlayConnect Playgroups, which provide a tailored play environment designed to meet the needs of children with ASD
 - ASD Early Days Workshops provide information for parents and carers of pre- school and school aged children with ASD
 - Medicare items are available for the development of a treatment plan and provision of up to 20 allied health services
 - Autism Specific Early Learning and Care Centres in six locations throughout Australia.
- **The Better Start for Children with a Disability (Better Start) initiative** — aims to improve access to early intervention therapies for children with disabilities that affect their development. Sight and hearing impairments, Down syndrome, cerebral palsy and Fragile X syndrome are the disabilities included under this package. Supports provided under the initiative include access to funding of up to \$12,000 (up to a maximum of \$6,000 per financial year) for early intervention services, and new Medicare items for a treatment and management plan, diagnostic services and up to 20 allied health treatment services.

The focus of this report is on the Better Start initiative. Given the similarities between HCWA package and Better Start, however, it is likely that many of the findings in this report will have relevance to other Australian Government work.

However, the conclusions outlined in this report are intended to be read in relation to that initiative only.

Broader context — towards a National Disability Insurance Scheme

The Productivity Commission's final report into a National Disability Insurance Scheme was released on 10 August 2011. The Commission recommended establishment of an NDIS to fund supports for people with significant disability. The scheme is proposed to begin roll out in mid 2014, taking full effect in mid 2018.²⁷

The report provides little detail about how existing service providers — including ECI service providers — will specifically operate or be funded under a future NDIS. However, more broadly it recommends that a key aim of the NDIS should be to increase the choice people with disability have over their supports. It proposes an 'individual choice' model where people with disability choose how much control they want, from selecting only a service provider to cashing out their eligible funding and gaining full control, subject to some conditions.

It is not clear to what extent this broad principle of choice for people with a disability will extend to children with a disability or developmental delay and their families. The Productivity Commission does describe the current challenges and opportunities relating to early intervention, and outlines some of the key areas for future work in relation to supporting people with a disability and their carers. However, much of the Commission's focus with respect to these issues relates to the systems overseen by state and territory governments. In this context, it is important to note that a key feature of the Australian Government's *HCWA* package and the *Better Start* initiative is the significant choice they provide to families. As such, the Australian Government's current approach to supporting children with a developmental disability and their families is consistent with the high level directions articulated for the NDIS.

The Australian Government has given in-principle support to establish a National Disability Insurance Scheme. In developing the NDIS, further work is required to:

- develop assessment tools to determine eligibility for support
- develop service and quality standards
- develop a national pricing structure
- build the capacity of the disability sector
- build workforce capacity.

The NDIS represents a significant opportunity to refine policy and programs relating to support for children with a disability and their families.

²⁷ Productivity Commission 2011 *Disability Care and Support*, Productivity Commission Report no. 54, Productivity Commission, Canberra.

In its response, the Australian Government has committed to build the foundations of an NDIS and to:

- develop common assessment tools to determine eligibility for support
- develop service and quality standards so that people with disability can expect high quality support irrespective of what disability they have or how they acquired it
- develop a national pricing structure
- build the capacity of the disability sector
- build workforce capacity.

The outcomes from this policy work may significantly impact the future funding and operating arrangements of disability service providers broadly and early childhood intervention services more specifically. In particular, the development of a new national pricing structure for all disability supports could impact the structure and funding of early intervention. However, the significant flexibility of funding already provided to eligible families under the Australian Government's HCWA package and Better Start initiative has significant parallels with the proposed approach to funding under the NDIS.

The development of an NDIS is in its infancy, and will draw on current practice as much as it dictates new approaches. While it would be ineffective to cease refining policy relating to early intervention approaches while an NDIS is developed, policy makers should not ignore opportunities that the NDIS presents to reform existing approaches.

3 Literature review — responding to four key questions

This chapter reviews the early childhood intervention literature to respond to four broad questions:

- Is early intervention generally associated with improved outcomes for childhood developmental disabilities?
- Does early intervention assist children with developmental disabilities in making a successful transition to school?
- Does early intervention have an association, either direct or indirect, with social and workforce participation later in life?
- What current research is available comparing the use of diagnostic or functional thresholds to determine eligibility for early intervention, and what are the design features of a tool that could determine eligibility for assistance?

Emerging themes in early intervention theory and practice

As outlined in 1 — About this project, KPMG has been engaged to consider a range of questions relating to the evidence supporting early childhood intervention for children with a developmental disability or delay. Four of those questions relate to the research literature on early childhood intervention:

- Is early intervention generally associated with improved outcomes for childhood developmental disabilities?
- Does early intervention assist children with developmental disabilities in making a successful transition to school?
- Does early intervention have an association, either direct or indirect, with social and workforce participation later in life?
- What current research is available comparing the use of diagnostic or functional thresholds to determine eligibility for early intervention, and what are the design features of a tool that could determine eligibility for assistance?

This section considers these questions in turn, in the context of emerging themes in early childhood intervention theory and context.

Research limitations

At the outset, it is important to reiterate that while there is a significant body of research on the effectiveness of early childhood intervention in general, little evidence exists that directly responds to the four questions posed. As the commissioners of the UK Government's Commission on Early Intervention have observed, not having strong evidence on how early intervention programs respond to children with varying needs creates an issue of equivalence. Because much of the evidence on the effectiveness of early childhood intervention relates to universal programs, it is difficult to anticipate how effective interventions might be in responding to specific needs.²⁸

For this reason, KPMG has analysed large, universally-based longitudinal cohort studies to infer findings relevant to the questions outlined above. These studies describe a diverse range of programs, spanning:

²⁸ Allen 2011 *Early Intervention — The Next Steps*, UK Commission on Early Intervention, London, March, p. 59.

- Early childhood education — programs focused on providing education for children predominately through childcare or kindergarten services. In some programs, the formal education given in an out-of-home setting is supported by home visits.
- Home-visiting or parent education — programs directed at improving the skill-set of parents, either through trained individuals conducting a home-visit or through classroom based training.
- Early intervention for children with a disability — programs directed at children with a particular condition that might include elements such as childhood education, home-visiting or parent education, but which are considered separately to programs that target mainstream education, due to the unique needs of children with disabilities.

Several criteria determined whether programs were included in this report. First, programs focused on improving the outcomes for children through early intervention were included. In particular, programs that considered the long-term effects of early intervention on participants when they entered school, or became adults, were relevant to the analysis outlined here.

Second, programs that targeted individuals from different backgrounds and with diverse requirements were included, to provide an understanding of the probable outcomes for a variety of children in different environments and with different needs.

Is early intervention generally associated with improved outcomes for childhood developmental disabilities?

The early years are the most important years in terms of human development. Evidence from across the scientific, developmental and economic spheres emphasises the impact of healthy development during childhood on a range of outcomes later in life.

Early brain development can determine children's health and wellbeing in later life. Neuroscientific research shows that the 'neural circuits' for coping with stress are significantly shaped during the antenatal period through to early childhood. As a result, and as the findings of the UK EPPE study conclude,

Early childhood intervention is associated with improved outcomes for children with a broad range of vulnerabilities — including disability.

However, evidence for the broad social and developmental impacts of ECI on children with a developmental disability is insufficient to definitively resolve this issue.

early emotional experiences can ‘literally become embedded in the architecture of the brain’.²⁹

Given the importance of the early years, ECI practitioners argue that early intervention is critical for responding to children’s developmental needs as early as possible. For children with developmental disabilities, the research literature suggests that the intervening early is even more important than for children more generally, since learning is cumulative, and therefore barriers to healthy development early in children’s lives impedes development at each subsequent stage.³⁰

The UK Commission recently established to identify options for early intervention has described this cumulative effect:

Studies have also found a link between low maternal responsiveness at 10–12 months to aggression, non-compliance and temper tantrums at 18 months; lower compliance, attention-getting and hitting at 2 years of age; problems with other children at 3; coercive behaviour at 4; and fighting and stealing when the child is 6. Low maternal responsiveness at 18 months did not seem to have this effect, consistent with the hypothesis that windows for development make the timing of deprivation — that period when it takes place — significant.³¹

Much of the research on the effectiveness of early intervention can be characterised in one of two ways. First, there are large, generalist early intervention programs that aim to respond to a range of vulnerabilities impacting on children, including disability or developmental delay. The second broad category of research evidence describes individual programs that adopt a specific intervention to respond to a well-defined (usually diagnostically-based) need or condition. The following section describes the outcomes achieved by a number of these examples.

²⁹ Sylva K, Melhuish E, Sammons P, Siraj-Blatchford I and Taggart B (2004) *The Effective Provision of Pre-school Education (EPPE) Project: Final Report. Findings from Pre-school to the End of Key Stage 1*, Department for Education and Skills, London.

³⁰ Heckman J. and Masterov D. 2007 ‘The productivity argument for investing in young children’ in *Review of Agricultural Economics* 29(3): 446–93; and Perry B 2002 ‘Childhood experience and the expression of genetic potential: what childhood neglect tells us about nature and nurture’, in *Brain and Mind*, 3: 79–100.

³¹ Allen 2011 *Early Intervention — The Next Steps*, UK Commission on Early Intervention, London, March, p. 16.

General, universally-based preschool programs

A number of early intervention programs, such as the Perry Preschool and Abecedarian programs, build from a strong, universal service platform, and respond to children with a range of strengths and needs — including children with developmental disabilities. The box below describes the Perry Preschool program, and outlines its target group, approach and outcomes. As this box illustrates, the program does include a target cohort that includes a majority of children with a IQ score that would be borderline for inclusion in early childhood intervention services in Australia. The program demonstrates effectiveness in improving broad developmental and social outcomes for program participants.

Exhibit 2

The Perry Preschool program demonstrated significant improvements in children's IQ scores immediately after the program was completed.

Program participants also:

- required less support later in life and
- were more likely to participate in the labour force
- reported significantly higher wages than non-participants.

Perry Preschool

The overall aim of the Perry Preschool³² program was to determine whether providing preschool education would improve the emotional, social and intellectual development of children in preparation for school.

Target

The Perry Preschool program operators determined which children were eligible to participate in the program. Their decision was based on an assessment of whether a child was likely to underperform in school. The majority of participants:

- had a low IQ score, from 70 to 85 — in the range indicating borderline intellectual disability
- had parents had low educational attainment, either high school or less
- had parents had low occupations status, either unemployed or unskilled, and
- lived in households categorised as 'low socioeconomic status'.

³² There were several studies used for this section of the report about Perry Preschool, namely: Ellen Galinsky, "The Economic Benefits of High-Quality Early Childhood Programs: What Makes the Difference"; Peter Muenning, "Effects of a Prekindergarten Educational Intervention on Adult Health: 37-Year Follow-Up Results of a Randomized Controlled Trial", *American Journal of Public Health*, Volume 99, Number 8, August 2009, pp. 1431 - 1437

Approach

In total, 123 children participated in the Perry Preschool program, which ran from 1962 to 1967. Each year, 20 to 25 children entered the program. The children participated in part-day, high quality, daily preschool for one to two years.

The teachers followed the “Cognitively-Orientated Curriculum”, which was based around the idea that children should not be directly instructed but rather, encouraged to make their own plans, carry them out and report back afterwards. Galinsky contends that teachers encouraged children to make their own choices. Teachers helped extend these choices to aid development.

In addition to the preschool, a trained professional visited families for an hour and a half per week. The purpose of this visit was to teach parents how to monitor their child’s development and how to provide experiences to further their child’s learning.

Outcomes

Directly after the program concluded, the IQ of participants was 12 points higher than the control group’s IQ. 67 per cent of program participants had an IQ of approximately 90, compared to 28 per cent of the control group. There were also notable differences between participants in the Perry Preschool program and the control group, including:

- 15 per cent of participants needed special education services by the age of 15, compared to 34 per cent of the control group;
- At age 27, 71 per cent of participants had graduated high school compared to 54 per cent of the control group;
- At age 27, 79 per cent of preschool participants were employed, compared to 59 per cent of the control group; and
- The average weekly earning of preschool participations was US\$1219, compared to \$766 for the control group.

Source: Ellen Galinsky, “The Economic Benefits of High-Quality Early Childhood Programs: What Makes the Difference”; Peter Muenning, “Effects of a Prekindergarten Educational Intervention on Adult Health: 37-Year Follow-Up Results of a Randomized Controlled Trial”, American Journal of Public Health, Volume 99, Number 8, August 2009, pp. 1431 - 1437

While the Perry Preschool program and other universally-based programs have been shown to be effective, their generality means it is not clear how effective they are for children with a developmental disability specifically.

Specialist, targeted interventions

Another category in the research literature evidence relates to programs that adopt a specific intervention to respond to a well-defined (usually diagnostically-based) need or condition. This type of research often comes from a therapeutic frame of reference, and describes the efficacy of specific approaches that can help to improve a child's functioning.

The Building Blocks program illustrates this more focused category of evidence. It is described below, along with its targeting rationale, service approach and outcomes.

Exhibit 3

The Building Blocks program supports children with an autism spectrum disorder. It demonstrates significant improvements in children's outcomes, including:

- improvements in behaviour, as assessed using the Vinelands Adaptive Behavioural Scales.

Aspects Building Blocks

Autism Spectrum Australia (Aspects) is a not-for-profit organisation that aims to assist individuals with autism spectrum disorder across Australia. One of Aspects' programs is Building Blocks³³, which provides early interventions to aid children and their families.

Target

Eligible children for the Building Blocks program are aged between birth and 7 years and have been diagnosed with an autism spectrum disorder.

Approach

The Building Blocks program provides both a home-based service and a centre-based service. The home-based service involves a staff member from the Building Blocks program working with a child and their family to develop their specific needs. Each program is individualised in conjunction with the child's parents as well as other individuals involved in the child's care. Often the program focuses on improving parents' ability to manage their child's

³³ Information for this section of the report about Signposts was based on the study by Jacqueline Roberts, Katrina Williams, Mark Carter, David Evans Trevor Parmenter, Natalie Silove, Trevor Clark and Anthony Warren, "A Randomised Controlled Trail of Two Early Intervention Programs For Young Children with Autism: Centre-Based with Parent Program and Home-Based", *Research in Autism Spectrum Disorders*, Volume 5, 2011, pp. 1553-1566

behaviour in a positive manner. Children involved in the home-based program are visited once a fortnight for two hours, for a 40 week period.

The centre-based program involves a play-group component, as well as a parent training session, which run concurrently. The playgroup component is organised similar to a preschool program with the goal of preparing children to enter a mainstream program. Staff implement activities that encourage the development of social play skills and communication. While the children are engaged in the preschool, parents are given the opportunity to participate in a session to discuss a range of predetermined topics with staff and other parents. Parents are also encouraged to develop a support network. The centre-based program is held for two hours every week over a 40 week period.

Outcomes

In Roberts et al.'s study of the Building Blocks program, outcomes from the centre-based group, the home-based group, and a waiting list group (effectively a control group) were compared.

The results found that there were statistically significant improvements in all three groups on the communication scale of the *Vineland Adaptive Behaviour Scales*. Children in the centre-based program had the largest improved (78.4 after the program compared to 64.4 before the program) followed by the waiting list (74.2 after the program compared to 68.5 before the program), the home-based group had the smallest increase (68.4 after the program compared to 64.4 before the program). No other changes were statistically significant.

Roberts et al. noted that a severe weakness of their study was the heterogeneity of the autism population, which plagues many autism studies. Indeed, despite the randomised assigning of children to groups, children in the home based group had on average more severe autism.

Source: Jacqueline Roberts, Katrina Williams, Mark Carter, David Evans Trevor Parmenter, Natalie Silove, Trevor Clark and Anthony Warren, "A Randomised Controlled Trial of Two Early Intervention Programs For Young Children with Autism: Centre-Based with Parent Program and Home-Based", Research in Autism Spectrum Disorders, Volume 5, 2011, pp. 1553-1566

While many of these studies demonstrate effectiveness in improving children's functioning, the specificity of much of this research means that it is not

possible to extrapolate findings on effectiveness to a broader cohort of children with a range of diagnostic or functional needs. Further, many of these studies do not evaluate the effectiveness of interventions in improving other, broader outcomes.

General characteristics influencing program effectiveness

A number of themes from both the generalist and specialist literatures provide evidence on the characteristics of effective programs for a range of children with developmental disabilities. These themes are discussed in turn.

'Early' means early

As was discussed in 1 — *Project context*, there is a significant body of work across neuroscience, psychology and economics that emphasises the importance of the early years in promoting healthy development. The first three years provide a foundation for all subsequent development.³⁴ Because learning is cumulative, and as Heckman and Masterov have observed, that 'learning begets learning'³⁵, it is important that children who are having difficulty learning key skills and behaviours early in life are supported as soon as possible so as not to impede their ongoing, cumulative development.

Further, the opposite argument is also true. Because 'learning begets learning', early intervention is important in ameliorating the impact of destructive environments or relationships on children's growth, before children's social and emotional responses to their emerging needs become set.³⁶

As a number of studies emphasise, however, *the earlier interventions can be provided when a need is identified, the more effective those interventions become.*³⁷

³⁴ Shore R. 1997 *Rethinking the Brain: New Insights into Early Development*. New York, NY: Families and Work Institute.

³⁵ Heckman J. and Masterov D. 2007 'The productivity argument for investing in young children' in *Review of Agricultural Economics* 29(3): 446–93; and Perry B 2002 'Childhood experience and the expression of genetic potential: what childhood neglect tells us about nature and nurture', in *Brain and Mind*, 3: 79–100.

³⁶ Allen G 2011 *Early intervention — the next steps, Independent report to the UK Government*, Final Report of the Early Intervention Review, London, pp. 5-6.

³⁷ See, for example, Sylva K, Melhuish E, Sammons P, Siraj-Blatchford I and Taggart B (2004) *The Effective Provision of Pre-school Education (EPPE) Project: Final Report. Findings from Pre-school to the End of Key Stage 1*, Department for Education and Skills, London; Shonkoff, J

Family centred practice — reducing the ‘chaos’ families manage

A number of studies described how accessing early childhood intervention supports adds significant complexity to the lives of children with a developmental disability and their families.³⁸ Families report that supporting a family member with a disability imposes an emotional cost that can worsen mental health outcomes in families and reduce overall family health and functioning.³⁹ This complexity has been described in the literature as the early intervention ‘maze’, through which families must stumble in order to access the support they need.⁴⁰

Consequently, researchers report that early childhood intervention is most effective when families are provided with coordinated support that is designed and delivered with their unique needs and circumstances in mind, that is, family-centred. The effect of a coordinated range of supports is to provide families who are accessing ECI with a coherent set of supports that allow children to work towards a consistent set of goals across a variety of environments in which they live and learn.⁴¹

To achieve this sense of a coordinated support system, some researchers describe the capacity for services to be arranged in both ‘interdisciplinary’ and ‘transdisciplinary’ ways. *Interdisciplinary* approaches bring together professionals with different backgrounds and expertise to achieve a specific objective for a child and their family. This approach could introduce a ‘team

and Meisels S (eds.) 2000, *Handbook of Early Childhood Intervention*, Cambridge, UK, Cambridge University Press; and Siraj-Blatchford, I. 2007 The case for integrating education with care in the early years. In Siraj-Blatchford, K. Clarke and Needham M. (eds.) *The Team Around the Child: multi-agency working in the early years*, Trentham Books, Stoke on Trent, UK.

³⁸ Edwards B, Higgins D, Gray M, Zmijewski N & Kingston M 2008. *The nature and impact of caring for family members with a disability in Australia*. AIFS Research Report No. 16. Australian Institute of Family Studies, Melbourne.

³⁹ Edwards B, Higgins D, Gray M, Zmijewski N & Kingston M 2008. *The nature and impact of caring for family members with a disability in Australia*. AIFS Research Report No. 16. Australian Institute of Family Studies, Melbourne.

⁴⁰ For example, Association for Children with a Disability 2010, *Through the Maze — An overview of services and support for parents of children with a disability in Victoria*, 6th Edition 2010–2011, Association for Children with a Disability, Melbourne.

⁴¹ Centre for Community Child Health 2010 *Early childhood intervention services — Revised literature review*, report to the Victorian Government Department of Education and Early Childhood Development, Melbourne, December.

around the child'⁴² that would be able to draw on specialist training from across the range of professional disciplines with which families engage in the course of their early intervention journey. *Transdisciplinary* approaches take this concept of collaboration further. A transdisciplinary approach usually involves one professional leading a team comprising potentially many professionals. The fact that a single professional brings this team of specialists together give families continuity and coherence, and can significantly reduce the number of different professionals with whom a family must come into contact.⁴³

Intervening in children's 'natural environments'

The research literature presents a third significant theme related to the question of ECI effectiveness. The literature on effective ECI practice — and particularly the work of Carl Dunst — emphasises the importance of intervening in children's everyday learning environments — including in their homes.⁴⁴ As Dunst notes, children are presented with opportunities to learn and practice skills in the course of their everyday lives. Effective interventions take advantage of these natural learning opportunities, and ensure that the environments in which children spend the most time support their acquisition of new skills and refinement of old ones.

Dunst's understanding of the capacity of early intervention to occur throughout children's lives fundamentally changes the traditional understanding of ECI. As the Centre for Community Child Health observes:

If early childhood intervention is defined in terms of providing children with experiences and opportunities that promote competencies that enable them to participate meaningfully in home and community environments then the focus will be on ensuring that families and other

⁴² See Limbrick, P 2001 *The Team Around the Child: Multi-agency service co-ordination for children with complex needs and their families*, Interconnections, UK; and Limbrick, P 2009 *TAC for the 21st Century: Nine Essays on Team Around the Child*, Interconnections, UK.

⁴³ Muir K Tudball J & Robinson S 2008 *Family resilience where families have a child (0-8) with disability*, Social Policy Research Centre, University of New South Wales, Sydney.

⁴⁴ Dunst, C 2006 Parent-mediated everyday child learning opportunities: I. Foundations and operationalisation, *CASEinPoint*, 2 (2), 1-10.

http://www.fippcase.org/caseinpoint/caseinpoint_vol2_no2.pdf

Dunst, C 2007 Early intervention for infants and toddlers with developmental disabilities. In S.L. Odom, R.H. Horner, M.E. Snell and J. Blacher, J. (eds.), *Handbook of Developmental Disabilities*, Guilford Press New York.

Dunst, C. 2007 *Social-emotional consequences of response-contingent learning opportunities*, (Winterberry Research Syntheses Vol. 1, No. 16 Winterberry Press, New York.

carers are able to provide children with such experiences and opportunities. In other words, the aim will be to ensure that the child's everyday learning environments are optimal.⁴⁵

Seeing ECI in this way reframes the traditional conception of interventions as 'the major agent of change through direct work with children'⁴⁶ to one where ECI supports families to 'ensure that the children's everyday environments provide them with the opportunities and experiences that will enable them to develop the functional skills to participate meaningfully'.⁴⁷

As Siraj-Blatchford has observed, early childhood education and care settings represent a key 'natural environment' in which children learn. As such, there is a strong case for integrating early childhood services, such as childcare or preschool services, with ECI services.⁴⁸

While there is some evidence to suggest that generalist programs support children with a range of vulnerabilities to successfully transition to school, there is less evidence relating specifically to children with developmental disabilities. However, a number of interventions aimed specifically at children with a developmental disability improve a range of learning outcomes, from which it is possible to infer improvements in school transitions.

Does early intervention assist children with developmental disabilities in making a successful transition to school?

Early interventions have been demonstrated to improve educational outcomes — including transitions to school — for children with a range of vulnerabilities. From the generalist research literature, it is clear that interventions such as quality early childhood education increase children's participation in a range of community activities – including schooling – later in life. Evidence from the Sure Start program in the UK emphasises that a strong, low cost intervention makes a difference in helping children and their families prepare for engagement with formal community activities – including schooling.⁴⁹

Other studies, also from the UK, suggest that general early interventions, such as quality childcare, improve children's intellectual, social and behavioural skills at school entry.⁵⁰ Further, longitudinal analysis of children's outcomes

⁴⁵ Centre for Community Child Health 2010 *Early childhood intervention services — Revised literature review*, report to the Victorian Government Department of Education and Early Childhood Development, Melbourne, December, p. 36.

⁴⁶ Ibid. p. 91.

⁴⁷ Ibid. p. 91.

⁴⁸ Siraj-Blatchford, I. 2007 'The case for integrating education with care in the early years' In Siraj-Blatchford, K. Clarke and Needham M. (eds.) *The Team Around the Child: multi-agency working in the early years*, Trentham Books, Stoke on Trent, UK.

⁴⁹ Allen G and Duncan Smith I 2008 *Early Intervention: Good Parents, Great Kids, Better Citizens*, Centre for Social Justice and the Smith Institute, London.

⁵⁰ Sylva K, Melhuish E, Sammons P, Siraj-Blatchford I and Taggart B (2004) *The Effective Provision of Pre-school Education (EPPE) Project: Final Report. Findings from Pre-school to the End of Key Stage 1*, Department for Education and Skills, London.

suggests that the effect of these interventions persists long into children's schooling.⁵¹

Evidence from the US supports these findings on the efficacy of generalist interventions in improving school readiness for children with a range of vulnerabilities – including a developmental disability or delay. The following box describes the Abecedarian project, a large project delivered from a strong universal program base. The intervention was effective in improving learning outcomes for children well into their school experiences.

The Abecedarian Project delivers high quality early childhood education to children identified as being exposed to a range of risks. Children who participated in the project experienced better outcomes than non-participants in a control group, including:

- higher participation in higher education
- lower involvements with the criminal justice.

Exhibit 4

The Abecedarian Project

The Abecedarian project⁵² was a controlled scientific study of the potential benefits of early education for children living in high-risk environments. The overall goal of the study was to determine whether long-term positive outcomes could be generated for high-risk children by providing high-quality education from birth through to kindergarten.

Target

The Abecedarian project consisted of 111 children, born between 1972 and 1977, who were randomly assigned to either the early education program or to the control group. Participation was based on 13 socio-demographic factors that were weighed and aggregated to generate a high-risk index. These factors included family income, the level of maternal and paternal education and the age of the mother.

Notable characteristics of participants in the study included that the majority of children were living with a parent who was not married and who reported no earned income. In addition, the mothers of participants reported a low level of education; on average only 10 years of schooling had been obtained.

⁵¹ Sylva K, Melhuish E, Sammons P, Siraj-Blatchford I and Taggart B 2004 *The Effective Provision of Pre-School Education (EPPE) Project: Final Report from the Primary Phase: Pre-school, School and Family Influences on Children's Development During Key Stage 2 (Age 7–11)*, Department for Education and Skills Research Report 061, London.

⁵² There were several studies used for this section of the report about the Abecedarian Project, namely: Frances A. Campbell, Craig T. Ramey, Elizabeth Pungello, Joseph Sparling and Shari Miller-Johnston, "Early Childhood Education: Young Adult Outcomes From the Abecedarian Project", *Applied Developmental Science*, Volume 6, Number 1, 2002, pp. 42-5; Ellen Galinsky, "The Economic Benefits of High-Quality Early Childhood Programs: What Makes the Difference", *The Committee for Economic Development*, February 2006.

Approach

Children entered the Abecedarian program from the age of six weeks to three months. Participants were enrolled in full-day child care with the program beginning at 7:30am and finishing at 5:30pm for 50 weeks of the year. The program concluded when the participants entered kindergarten at age five.

The program was child centred and individualised depending on a child's needs. Craig Ramey, the program designer, was determined that the program operators would be spontaneous and fun, whilst encouraging learning.

After the formal program concluded, the program organisers were concerned that the benefits of the program would not be sustained. Accordingly, they created an initiative for the first three years of a participant's public school education. During the three years, families were provided with a home-school resource teacher who visited the family home on a bi-weekly basis to liaise between school and home and encourage parental involvement in the children's learning.

Outcomes

Participants in the study were evaluated at the conclusion of the program, when they were eight years of age and again at ages 12, 15, and 21. When the participants of the program were compared with the control group, at each age, the participants had achieved greater life success.

At age 21, there were notable differences across several indicators, including:

- 70 per cent of participants had graduated high school compared to 67 per cent of the control group;
- 36 per cent of participants were enrolled in a 4-year college course compared to 14 per cent of the control group; and
- Only 14 per cent of participants reported being incarcerated compared to 21 per cent of the control group.

Source: Frances A. Campbell, Craig T. Ramey, Elizabeth Pungello, Joseph Sparling and Shari Miller-Johnston, "Early Childhood Education: Young Adult Outcomes From the Abecedarian Project", Applied Developmental Science, Volume 6, Number 1, 2002, pp. 42-5; Ellen Galinsky, "The Economic Benefits of High-Quality Early Childhood Programs: What Makes the Difference", The Committee for Economic Development, February 2006.

So far, this section has built on findings from the generalist, rather than the specialist, literature on early intervention. In large part, this is due to the absence of a focus on school readiness in the literature describing the efficacy of specific interventions for children with specific needs. While this absence represents a gap in the research literature, the evidence from the generalist literature is strong and should not be dismissed. In particular, the generalist literature emphasises the importance of building early interventions from a strong universal base. The Chicago Child-Parent Centres emphasise the effectiveness of interventions that build from a universal service foundation, as described in the box below.

The Chicago Child-Parent Centres delivered education-based intervention to children from disadvantaged backgrounds. It demonstrated significant benefits, including:

- reduced contact with child protection systems among program participants
- improved educational outcomes.

Exhibit 5

The Chicago Child-Parent Centres

The Chicago Child-Parent Centres⁵³ was a federally funded program that provided early education services for children. The overall aim of the program was to improve the school success of children who were from low socioeconomic backgrounds.

Target

Children from a low socioeconomic background were eligible to participate in the study. The longitudinal study undertaken by Reynolds et al. (2011) provided an overview of the characteristics of the types of families who entered the Chicago Child-Parent Centres program in 1979-80. For example:

- 13.9 per cent of participants were from a vulnerable home environment;
- 16.4 per cent of participants had a parent under the age of 18 at birth;
- 50.5 per cent of mothers had not completed high school;
- 76.3 per cent of participants were being raised by a single parent; and
- 7.5 per cent of the families had financial problems.

⁵³ There were several studies used for this section of the report about Chicago Child-Parent Centre, namely: Ellen Galinsky, "The Economic Benefits of High-Quality Early Childhood Programs: What Makes the Difference"; Arthur Reynolds, Judy Temple, Barry White, Suh-Ruu Ou and Dylan L. Robertson, "Age 26 Cost-Benefit Analysis of the Child-Parent Centre Early Education Program", *Child Development*, January/February 2011, Volume 82, Number 1, pp. 379-404; Liza M. Conyers, Arthur J. Reynolds and Suh-Ruu Ou, "The Effect of Early Childhood Intervention and Subsequent Special Education Services: Findings from the Chicago Child-Parent Centres", *Educational Evaluation and Policy Analysis*, Volume 25, Number 1, Spring 2003, pp. 75-95

Approach

The Chicago Child-Parent Centres were first introduced in 1967. Initially, the centres were established in four schools and expanded to 25 schools by the mid-1970s. Children who were enrolled in the study attended the program for a half-day, five days per week during the school year. The program provided children with various opportunities, which included working in a large group, in smaller groups and on their own. There was a strong focus on children receiving individual attention.

In addition, there was a family support component, which involved parents volunteering in the classroom, attending school fieldtrips and general parental skill training. Furthermore, families had access to outreach activities, such as health screening, meal services and home visitation. When participants completed the program, they were transitioned into a linked kindergarten. The program concluded when the child completed the third grade at age 9.

Outcomes

There were many significant benefits of the preschool intervention including:

- Only 5.2 per cent of participants were placed in out of home care, compared to 8.5 per cent of the control group.
- Participants had a 6.8 per cent higher rate of high school graduation compared to the control group;
- Only 14.3 per cent of participants reported substance misuse, compared to 18.8 per cent of the control group; and
- Only 13.3 per cent of participants reported being arrested for a felony crime compared to 17.8 per cent of the control group.

As a ratio of benefits to costs, the intervention returned US\$10.83 per dollar invested.

Source: Ellen Galinsky, "The Economic Benefits of High-Quality Early Childhood Programs: What Makes the Difference"; Arthur Reynolds, Judy Temple, Barry White, Suh-Ruu Ou and Dylan L. Robertson, "Age 26 Cost-Benefit Analysis of the Child-Parent Centre Early Education Program", Child Development, January/February 2011, Volume 82, Number 1, pp. 379-404; Liza M. Conyers, Arthur J. Reynolds and Suh-Ruu Ou, "The Effect of Early Childhood Intervention and Subsequent Special Education Services: Findings from the Chicago Child-Parent Centres", Educational Evaluation and Policy Analysis, Volume 25, Number 1, Spring 2003, pp. 75-95

Both generalist and specialist interventions report success in improving social and workforce participation outcomes for children later in life.

Further, evidence also exists for the improvements in social and workforce participation of families of children with a developmental disability.

Does early intervention have an association, either direct or indirect, with social and workforce participation later in life?

There is a relatively strong evidence base from which to consider the role of both generalist and specialist programs in improving children's social and workforce participation later in life.

As has been discussed, economists have built on the scientific evidence on the importance of childhood to argue that society should invest in childhood development. In particular, Heckman and Masterov⁵⁴ describe analysis that suggests that there are potentially significant benefits associated with increasing government investment in programs that enhance children's development. In particular, this work notes that human capital is built up over the course of a lifetime and that learning in one life stage begets learning in the next.⁵⁵ As a consequence, Heckman notes that investment in childhood interventions increases children's productivity in each subsequent stage of life.⁵⁶

Caprara and Rutter have extended this rationale for early intervention's role in enhancing children's productivity. They have found that individuals who are vulnerable are more likely to experience ongoing difficulties as a consequence of their adversity.⁵⁷ Early intervention is therefore critical in these circumstances, since this evidence suggests that vulnerabilities 'attenuate' and compound over time in the absence of remedial efforts.⁵⁸

Reflecting this evidence, key researchers have observed that the current shape of government investment in children's development – that is, focused

⁵⁴ See in particular, Heckman J. and Masterov D. 2007 'The productivity argument for investing in young children' in *Review of Agricultural Economics* 29(3): 446–93; and Perry B 2002 'Childhood experience and the expression of genetic potential: what childhood neglect tells us about nature and nurture', in *Brain and Mind*, 3: 79–100.

⁵⁵ Cunha, F & Heckman, J 2010 *Investing in Our Young People*, NBER Working Paper Series, Vol. w16201, National Bureau of Economic Research Cambridge, Massachusetts. Available at: <http://ssrn.com/abstract=1641577>.

⁵⁶ Heckman, J 2004 'Invest in the very young' In Tremblay, Barr & De V Peters (eds.) *Encyclopedia on Early Childhood Development*, Centre of Excellence for Early Childhood Development, Montreal. Available at: <http://www.excellenceearlychildhood.ca/documents/HeckmanANG.pdf>.

⁵⁷ Caprara GV and Rutter M 1995 'Individual development and social change', in Rutter M and Smith DJ (eds.) *Psychosocial Disorders in Young People: Time Trends and Their Causes*, Wiley London.

⁵⁸ Allen G 2011 *Early intervention — the next steps, Independent report to the UK Government*, Final Report of the Early Intervention Review, London, p 25.

on children's acquisition of instrumental and vocational skills in their adolescents – is not consistent with the evidence on the importance of the early years. The Organisation for Economic Cooperation and Development has observed that:

*country spending profiles examined are not consistent with the theory and evidence on child well-being. In contrast there is little or no obvious rationale for why so many Governments place the weight of their spending on late childhood.*⁵⁹

As the OECD observes, there is a much greater weight of evidence supporting the view that early intervention improves the chances of children facing a range of vulnerabilities – including disability – participating more fully both socially in their communities and economically in the labour force.⁶⁰

A number of specialist programs also highlight the effectiveness of early childhood intervention in improving children's capacity to participate in broader social and economic life. The following boxes describe initiatives that improve children's social and economic participation. The first, which describes the Incredible Years Parenting program, illustrates how more targeted interventions can improve children's behaviour, facilitating smoother integration into a range of community activities.

Exhibit 6

The Incredible Years Parenting Program

The aim of the Incredible Years Program⁶¹ was to prevent and treat behavioural problems in children. There were several components of this program, including child, parent and teacher interventions. O'Neill's study analyses the training offered to parents as part of the Incredible Years Program in Ireland.

The Incredible Years Parenting Program demonstrated improvements in children's behaviour for children with an identified behavioural issue.

⁵⁹ Organisation for Economic Co-operation and Development (2009) *Doing Better for Children*, OECD, Paris, p. 94.

⁶⁰ Ibid.

⁶¹ Information for this section of the report about the Incredible Years Parenting Program" was based on the study by David O'Neill, "A Cost-Benefit Analysis of Early Intervention: Evidence from a Randomised Evaluation of a Parenting Programme", IZA, Discussion Paper No.4518, October 2009.

Target

The Incredible Years Parenting Program was aimed at all parents, but had a specific focus on parents who found their children's behaviour challenging.

Approach

Parents enrolled in the Incredible Years Program attended a two hour classroom based training session for 12 weeks. In these sessions, trained facilitators provided information on numerous aspects of parenting. O'Neill contends that the learning was founded on a collaborative approach between the facilitators and parents and that parents were also encouraged to form their own support networks with other parents in the training program.

Outcomes

Participants in the study were compared, using the Eyberg Test, to a control group. The Eyberg Test is a measure of childhood behavioural problems, with lower scores indicating fewer problems. Six months after parents participated in the Incredible Years Parenting Program, their children scored on average 20 per cent lower than children, whose parents were in the control group.

Source: David O'Neill, "A Cost-Benefit Analysis of Early Intervention: Evidence from a Randomised Evaluation of a Parenting Programme", IZA, Discussion Paper No.4518, October 2009.

First Voice, which represents services supporting children with hearing difficulties and their families, illustrates the outcomes that can be achieved from targeted interventions to improve economic participation outcomes.

First Voice represents interventions aimed at improving outcomes for children with a hearing impairment. It demonstrates the following improvements for participants:

- higher quality of life worth \$7,284 per annum
- higher school completion rates than a comparable group
- higher income over the life course.

Exhibit 7

First Voice

First Voice⁶² is a coalition of Australasian centres, which support children with hearing difficulties and their families. Centres are located in South Australia, Queensland, Victoria, New South Wales and New Zealand. The primary aim of the First Voice early intervention program is to provide specialist support to provide children with the best opportunity to fully develop spoken language.

⁶² Information for this section of the report about the First Voice program was based on the study, *EconnText, "Early Intervention Programs to Assist Children with Hearing Loss Develop Spoken Language"*, A report prepared for First Voice, 20 July 2011.

Target

The children eligible for the First Voice program have different types and degrees of hearing loss. Approximately 25 per cent of program participants have mild or mild-moderate hearing loss. At the other end of the spectrum, nearly one third of participants have severe-profound or profound-total hearing loss.

15 per cent of the program participants have additional special needs.

Approach

At the beginning of March 2011, 650 children in the pre-school age group were enrolled in First Voice early intervention programs. 610 of these children were enrolled in Australian programs, which was approximately one fifth of the children in that age group, and were fitted with hearing devices. Children entered the program as soon as possible after a diagnosis and graduated from the program at age five.

Participants and their families enrolled in the First Voice early intervention program are provided with intensive support. This includes auditory-verbal/oral therapy session, audiology sessions, child and family counselling sessions, home visits, pre-school and childcare visits, parents support groups, and information sessions.

Outcomes

A report prepared by Econtext (2001) found that the present (discounted) value of all costs per child enrolled in the First Voice program was AU\$203,307. In excess of 90 per cent of the total cost was incurred in the initial five years of the program when the child was enrolled in the intensive early intervention program.

The present (discounted) value of the benefits per child was \$382,894, which is AU\$152,587 greater than the costs. The AU\$382,894 worth of benefits is an aggregate measure of several key benefits to the program participant's life, including:

- Reduction in disability/better quality of life, valued at AU\$7,284 per year;

- 95.7 per cent of participants had finished Year 12. In comparison, the British Association of the Teachers of the Deaf reports that 86 per cent of deaf and hearing impaired students leave school by the age of 16 years;
- AU\$2,381 per year from age 6 to 17 worth of school costs avoided; and
- Higher income of AU\$10,327 per participant from age 18 onwards.

The benefit-to-cost ratio of the program is 1.9 to 1, which highlights that for every dollar invested in this program, there was almost two dollars worth of benefits in return.

Source: EconText, "Early Intervention Programs to Assist Children with Hearing Loss Develop Spoken Language", A report prepared for First Voice, 20 July 2011

However, while these descriptions focus on early childhood, they do emphasise that the relationships that children develop are vital because they facilitate social and emotional development, which is in turn strongly linked to cognitive growth, which is critical for social and economic participation at any age.⁶³

The examples outlined so far in this section describe programs that have improved the social and economic participation of children with a disability or developmental delay. However, an important consideration in the effectiveness of interventions is their capacity to improve families' overall functioning. Improving families' wellbeing supports those around a child with a disability or developmental delay to participate in both work and community activities. The Signposts for Building Better Behaviour program (below) highlights the positive impact ECI can have on the wellbeing of family members, and in turn on family functioning.

⁶³ Rogoff, B 2003 *The Cultural Nature of Human Development*, Oxford University Press, Oxford.

The Signposts for Building Better Behaviour program illustrates how ECI programs can improve the health and wellbeing of family members of children with an identified need.

The program demonstrated reduced stress among family members, and improves family members' capacity to participate in a range of social, community and economic activities.

Exhibit 8

The Signposts for Building Better Behaviour

The Signposts for Building Better Behaviour⁶⁴ program was developed between 1998 and 2000 jointly by the Parenting Research Centre and RMIT University. In 2005, the program was rolled out across Victoria. The preventative program is designed to assist parents of children aged between three and 16 who have an intellectual disability. In particular, the program aims to assist parents manage their child's difficult behaviour before it escalates to a stage where specialist care is required.

Target

The Signposts program is designed to be applicable to all parents with a child with an intellectual disability. In addition, grandparents, foster carers, child care staff and teacher aides who are involved in the care of a child with an intellectual disability are also invited to be involved in the program.

Approach

The Signposts Program consists of a number of educational materials for parents. The parent materials consist of approximately eight advice booklets which focus on how to manage difficult behaviour of children, a workbook and a DVD to support the content in the booklets. This information packet can be delivered by a practitioner in four ways, depending on the needs of the family, namely face-to-face in a group environment, face-to-face in an individual setting, via telephone or directly to the individual without additional support.

Outcomes

Hudson et al. (2008) measured the effect that the Signposts Program had on the parents who were involved. They found that:

⁶⁴ Information for this section of the report about Signposts for Building Better Behaviour program was based on the study by Alan Hudson, Christine Cameron and Jan Matthews, "The Wide-Scale Implementation of a Support Program for Parents of Children with an Intellectual Disability and Difficult Behaviour", *Journal of Intellectual and Developmental Disability*, Volume 33, Number 2, pp. 117-126

- On the Depression Anxiety Stress Scale (DASS) before participating in the program, the mean score for mothers' stress level was 13.8. After the program, the mean was 10.6.
- On the DASS before participating in the program, the mean score for fathers' stress level was 10.9. After the program, the mean was 8.7.

Source: Alan Hudson, Christine Cameron and Jan Matthews, "The Wide-Scale Implementation of a Support Program for Parents of Children with an Intellectual Disability and Difficult Behaviour", *Journal of Intellectual and Developmental Disability*, Volume 33, Number 2, pp. 117-126

Literature indicates that functional assessments, that consider both children's strengths and needs, and that consider the broader family context, are preferable to diagnostically-based assessment approaches.

A range of assessment tools exist, but would require modification and customisation for implementation in an Australian context.

What current research is available comparing the use of diagnostic or functional thresholds to determine eligibility for early intervention, and what are the design features of a tool that could determine eligibility for assistance?

Across the literature on early childhood intervention, there is recognition of the importance of assessment as a foundation of effective support for children and families. However, stakeholders identify the significant challenges in designing an assessment framework that is equitable and allows for effective targeting of supports.

Literature identifies a number of challenges in common approaches to assessment of the needs of children with a disability and their families. First, a prominent survey of carers' perceptions of disability support systems emphasises that processes for assessment of eligibility are difficult to understand and can lead to frustration with the service system.⁶⁵ Further, others have observed that assessment tends to involve the application of objective tools, that classify children and families in general categories.⁶⁶ Instead, these researchers propose that 'authentic assessment' – which involves ongoing matching of children's needs, strengths and environments – provides a more promising means of ensuring that interventions are current.⁶⁷

In addition, Carl Dunst has observed that assessment can be difficult for families, for two reasons. First, assessments have traditionally come from a

⁶⁵ Edwards B, Higgins D, Gray M, Zmijewski N & Kingston M 2008. *The nature and impact of caring for family members with a disability in Australia*. AIFS Research Report No. 16. Australian Institute of Family Studies, Melbourne.

⁶⁶ Bagnato, S 2005 'The authentic alternative for assessment in early intervention: An emerging evidence-based practice', in *Journal of Early Intervention*, 28, 17-22

⁶⁷ Bagnato, S 2007 *Authentic Assessment for Early Childhood Intervention: Best Practices*, The Guilford Press, New York.

deficit frame of reference that emphasises their weaknesses and what they cannot do. Second, assessments are often undertaken in clinical situations, with a professional who brings a treatment-based expertise to the assessment of children's and families' holistic needs.⁶⁸

In contrast, and as the Centre for Community Child Health has observed, experts from a range of disciplines have undertaken significant work to develop assessment tools that consider children's and families' needs in the context of their social and family environments.⁶⁹

Further, the universal early childhood service systems could provide a basis for identifying children and family needs as early as possible. As the UK review of early intervention observes, there is a significant opportunity for a range of key early childhood services to enhance children's readiness for school:

Universal services provided by GPs, hospitals, midwives, health visiting teams, children's centres, nurseries, schools, housing organisations and the police have all been shown to be effective in raising standards of physical health and/or educational attainment. However, they should now be more clearly charged with responsibility for improving standards of social and emotional well-being, and to recognise specifically the importance of the early years. In short, these agencies should all be working together to make sure that children are school ready.⁷⁰

Assessment methodologies

A number of tools have been developed to guide the functional assessment and determination of eligibility of children with a disability or developmental delay. This section briefly outlines a number of well-established approaches. The following discussion is intended to provide an overview on selected assessment approaches. It is not intended as an exhaustive summary of available programs, nor does it evaluate the efficacy or appropriateness of the assessments from a clinical point of view. For an authoritative summary of the

⁶⁸ Dunst, C 2011 'Advances in Theory, Assessment and Intervention with Infants and Toddlers with Disabilities', in Kauffman & Hallahan (eds.) *Handbook of Special Education*, Taylor & Francis, New York.

⁶⁹ Centre for Community Child Health 2010 *Early childhood intervention services — Revised literature review*, report to the Victorian Government Department of Education and Early Childhood Development, Melbourne, December.

⁷⁰ Allen G 2011 *Early intervention — the next steps, Independent report to the UK Government*, Final Report of the Early Intervention Review, London, p 54.

clinical issues regarding assessment from the point of view of specialist practitioners, Dunst and Trivette (2004) provide guidance – including a framework – for determining eligibility.⁷¹

Among the most well-established tools for determining children’s and families’ eligibility for early interventions are:

- the Bayley Scales of Infant and Toddler Development (Third Edition)
- the Vineland Adaptive Behavior Scale
- the Hawaii Early Learning Profile (HELP)

Bayley Scales of Infant and Toddler Development

The Bayley scales are primarily intended to be used to identify children with a developmental disability or delay and to guide families’ planning for accessing support. The tool involves a professional assessor providing information as part of the tool methodology, which involves family in the assessment process the tool is designed to assesses children in the five key domains of adaptive, cognitive, language, motor and social-emotional development.⁷²

Vineland Adaptive Behavior Scale

Like the Bayley Scales, the Vineland Scale is designed to help diagnose a range of developmental disabilities and delays. Unlike the Bayley Scales, however, the Vineland tool is organised around the three domains of communication, daily living, and socialisation. However, the Vineland tool does allow for the addition of two additional modular tools that include assessments against the domains of motor skills and maladaptive behaviour.⁷³

Hawaii Early Learning Profile

HELP is a curriculum-based assessment tool that is used to identify children and family needs and to tracking growth and development over time. HELP has also been used to guide interventions by giving families and professionals appropriate goals to work towards. The HELP assesses children’s regulatory and sensory organisation, cognitive, language, gross motor, fine motor, social

⁷¹ Dunst C & Trivette C 2004 ‘Toward a categorisation scheme of child find, referral, early identification and eligibility determination practices’, *Tracelines*, 1(2), 1–18. Available at: http://www.tracecenter.info/tracelines/tracelines_vol1_no2.pdf.

⁷² Bayley, N 2006 *Bayley scales of infant and toddler development—Third edition* Harcourt Assessment San Antonio.

⁷³ Sparrow S Cicchetti D & Balla D 2005 *Vineland II: A Revision of the Vineland Adaptive Behavior Scales: I. Survey/Caregiver Form*, American Guidance Service Circle Pines.

and self-help skills. A feature of the HELP is focus on the family as part of the assessment. The tool is administered as a family interview with a series of open-ended questions that help identify child and family needs. In this way, the HELP is used to determine interventions that will help meet both children and their families' needs.⁷⁴

Common features of different assessment approaches

While the three tools outlined above are not the only tools available, they were identified by a number of key stakeholders as being among the leading tools to guide functional assessments for children in the cohort served by Better Start. Each approach is different, but there are a number of principles running through both these tools and the broader literature on assessment methodologies that might provide the bases for further work in undertaking preliminary work towards establishing a functional assessment for children accessing ECI supports.

First, consistent with the research supporting 'authentic' approaches to assessment,⁷⁵ assessment should be conceived as dynamic and ongoing, rather than a static or periodic decision point. For ECI to be most effective, it should be flexible and reflect children's development and families' changing circumstances.

A second principle common across a number of assessment approaches is that assessment should reflect both children's strengths and needs in the context of the strengths and needs of the broader family.⁷⁶ Since children develop and learn in social, family and community settings, it is important to consider the impact of those environments on a child's likely support needs.

A third principle emerging from the literature on ECI assessment is the importance of ensuring that assessment is outcome-focused and directed towards realistic goals. For ECI to be most effective, it must be sensitive to

⁷⁴ Pretti-Frontczak K 2002 'Using Curriculum-Based Measures to Promote a Linked System Approach' in *Assessment for Effective Intervention* Summer 2002 vol. 27 no. 4 15-21.

⁷⁵ See Bagnato, S 2005 'The authentic alternative for assessment in early intervention: An emerging evidence-based practice', in *Journal of Early Intervention*, 28, 17-22; and Bagnato, S 2007 *Authentic Assessment for Early Childhood Intervention: Best Practices*, The Guilford Press, New York.

⁷⁶ Dunst C & Trivette C 2004 'Toward a categorisation scheme of child find, referral, early identification and eligibility determination practices', *Tracelines*, 1(2), 1-18. Available at: http://www.tracecenter.info/tracelines/tracelines_vol1_no2.pdf.

children's capabilities while at the same time directed towards meaningful objectives.⁷⁷

All of the tools outlined here have been designed for application internationally. While the tools outlined above are widely used, they are limited in considering the context that impacts on child and family functioning.⁷⁸ Consequently, before widespread adoption of any one tool as part of a government program of supports, further work would be required to customise the tool for broad implementation in an Australian context.

As was observed in 2 – *project context*, the World Health Organisation has undertaken significant work to develop the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY). This classification describes not only physical or activity limitations, but also restrictions on children and young people's participation and the environments they inhabit.⁷⁹ Some have described the potential for the ICF-CY to form the basis of an internationally-recognised assessment tool.⁸⁰ The ICF-CY would provide the basis for further development of a tool for assessing the functional needs of children and families in a way that is consistent with the rights-based conception of ECI outlined in 2 – *project context*.

Conclusions from the literature

This chapter has responded to four key questions relating to the effectiveness.

Is early intervention generally associated with improved outcomes for childhood developmental disabilities?

Early childhood intervention is associated with improved outcomes for children with a broad range of vulnerabilities — including disability. However, the evidence for the broad social and developmental impacts of ECI is stronger for a broad group of children than for children with a developmental disability

⁷⁷ Centre for Community Child Health 2010 *Early childhood intervention services — Revised literature review*, report to the Victorian Government Department of Education and Early Childhood Development, Melbourne, December.

⁷⁸ In contrast, see Madden R Ferreira M Einfeld S Emerson E Manga R, Refshauge K and Llewellyn 2011 'New directions in health care and disability: the need for a shared understanding of human functioning' [in preparation].

⁷⁹ Ibid.

⁸⁰ Anderson P, Madden R 2011 'Design and quality of ICF-compatible data items for national disability support services', *Disability and Rehabilitation*, 2011; 33(9):758-769

specifically. This notwithstanding, there is sufficient evidence to be able to suggest that a range of interventions improve outcomes for children with a developmental disability, particularly those that support both children and their families in children's 'natural environments'.

Does early intervention assist children with developmental disabilities in making a successful transition to school?

While there is some evidence to suggest that generalist programs support children with a range of vulnerabilities to successfully transition to school, there is less evidence relating specifically to children with developmental disabilities. However, a number of interventions aimed specifically at children with a developmental disability improve a range of learning outcomes, from which it is possible to infer improvements in school transitions. Further, ECI is often aimed at improving overall family functioning to support children's broader development. As such, while ECI may improve educational outcomes, these outcomes may not be the primary focus of interventions.

Does early intervention have an association, either direct or indirect, with social and workforce participation later in life?

Both generalist and specialist interventions report success in improving social and workforce participation outcomes for children later in life. For example, and as 3 – literature review outlines, large, universally-based program such as the Perry Preschool program and smaller, more targeted programs that work with children with specific needs, such as those supported by the First Voice group of services, report improvements in a variety of areas relating to social and workforce participation. (See 3 – literature review for more information).

Further, evidence also exists for the improvements in social and workforce participation of families of children with a developmental disability.

What current research is available comparing the use of diagnostic or functional thresholds to determine eligibility for early intervention, and what are the design features of a tool that could determine eligibility for assistance?

Literature indicates that functional assessments that consider both children's strengths and needs, and that consider the broader family context, are preferable to diagnostically-based assessment approaches.

A range of assessment tools exist to facilitate functional assessments for the cohort served by Better Start. However, these tools would require modification and customisation for implementation in an Australian context.

4 Cost effectiveness — the broad issues

This section of the report sets out the approaches and techniques that can be adopted in carrying out an economic assessment. KPMG then outlines the approach proposed to assess the potential benefits (and costs) for extending the current Better Start funding program to additional groups of children.

Analysing the cost effectiveness of intervention

A key aim for this report is to estimate the number of Australian children with a developmental disability, and to examine the cost implications — both short term costs and longer term benefits — of expanding current Australian Government funding for early intervention supports for these children and their families. This section of the report sets out the approaches and techniques that can be adopted in carrying out an economic assessment. It then proposes an approach to assess the potential benefits (and costs) of broadening the Better Start eligibility criteria to provide support for additional groups of children.

The analytical approach adopted in this report is an adaptation of a cost effectiveness analysis. KPMG has developed an adapted cost effectiveness framework because of the limited directly applicable evidence on the likely potential benefits of early intervention programs targeted at children with developmental delay (other than for certain, specific disabilities and conditions, and then only for a limited benefit horizon).

Framework for economic appraisal of intervention approaches

Conducting an economic assessment (especially with respect to human services programs, such as in the present case) necessarily involves tradeoffs between completeness, robustness and practicality. A range of applicable frameworks, and the tradeoffs involved with respect to each approach is set out in the following exhibit:

Exhibit 9

Approaches to Economic Analysis

Types of analysis	Measure of cost	Measure of outcomes	Strengths	Weaknesses
Cost-effectiveness	Monetary value of resources	Units of effectiveness (for example, improvement in academic test scores)	<p>Easy to incorporate standard evaluations of effectiveness</p> <p>Good for alternatives with small number of objectives</p>	<p>Hard to interpret when there are multiple measures of effectiveness</p> <p>Only useful for comparing up to two alternatives; outcome measures must be comparable</p>
Cost-benefit	Monetary value of resources	Monetary value of benefits	<p>Can judge absolute worth of a project</p> <p>Can compare CB results across a variety of projects</p>	<p>Difficult to place monetary values on many salient life benefits</p>
Cost-savings	Monetary value of resources	Monetary savings resulting from impact of intervention	<p>Good for assessing the savings generated to stakeholders</p>	<p>Difficult to place monetary values on many salient life benefits</p>
Cost-utility	Monetary value of resources	Units of utility	<p>Incorporates individual preferences for units of effectiveness</p> <p>Incorporates multiple measures of effectiveness into a single measure of utility</p>	<p>Difficult to arrive at consistent and accurate measures of individual preferences</p> <p>Cannot judge overall worth of a single alternative, only useful for comparing two or more alternatives</p>

Source: Matthew Manning, Ross Homel and Christine Smith, 2011, "An Economic Method for Formulating Better Policies for Positive Child Development", *Australian Review of Public Affairs*, Volume 10, Number 1, p.64

Generally, a cost-benefit analysis is considered to represent the 'first-best' approach to carrying out an economic appraisal. Ideally, such an assessment would involve the calculation of the lifetime costs and benefits of a set of programs, using an actuarial-style model for different cohorts of children. This approach would enable a comparison of outcome metrics (such as educational attainment and employment) for each cohort under different intervention scenarios. This approach would then enable the lifetime benefits of different interventions to be expressed in a common monetary terms,

allowing the calculation of the net benefits of different intervention programs. However, to effectively implement a cost-benefit framework, robust information on the net benefits of different intervention programs is required.

A limited number of studies have sought to assess (in a partial framework) the cost-benefit ratio of early intervention programs (the results of which are considered in the following section). Generally however, applying a cost-benefit framework in the absence of a detailed study framework is difficult — due to the absence of reliable data on the range of costs and benefits that may accrue.

An alternative approach, and one that is often used when undertaking an economic assessment of a range of policy options, is a cost effectiveness analysis (CEA)⁸¹. A CEA is often chosen over a cost benefit analysis where it is impractical to reduce the range of quantitative and qualitative benefits to a common monetary expression. In the current context, the range of possible benefits arising from the possible intervention options will include a mix of monetary costs and benefits and non-monetary costs and benefits, many of which likely cannot directly be assessed within a cost-benefit analysis framework (in particular, in the absence of a robust actuarial lifetime cost-benefit model). Generally, under a cost effectiveness analysis, once all costs and benefits over the life of the program have been identified and quantified, they should be expressed in present value terms where appropriate (for example, costs and benefits expressed in monetary terms, but not other measures).

A limitation of CEA (as compared to cost-benefit analysis) is that it is not possible to compare the value derived from a particular intervention or program that is the subject of the CEA, to the value derived from an unrelated program or intervention. In other words, the results of a CEA can provide insight into the relative value of different approaches to a particular policy or program, but cannot provide direct insight into the relative value of a policy or program generally.

⁸¹ Practically, CEA is equivalent to other partial assessment frameworks — such as cost-utility and cost-savings analysis. The key feature of each of these techniques is that benefits accruing to a particular program cannot be directly compared to benefits (or payoffs) from unrelated programs as can be done for a cost-benefit analysis.

Given this limitation, in establishing a framework for a CEA it is necessary to contrast particular approaches to the delivery of early intervention (and/or assess the value of early intervention programs generally, relative to other forms of intervention) in order to provide meaningful results.

Assessing the benefits of early intervention

As 3 — *literature review* outlines, studies on the effectiveness of early childhood intervention focus on the potential achievement of long-term significant improvements in the outcomes of participants. Early childhood interventions are directed at a variety of issues. Early intervention programs have been shown to improve outcomes related to health, education, employment, and crime.⁸² The reported benefits of early childhood intervention are likely to be greater for programs that successfully target children in high risk environments, than those that serve lower-risk children.⁸³ In these circumstances, children that were previously at risk are often able to achieve outcomes equal to, or even above, their peers.

In instances where young children are diagnosed with a particular condition or developmental delay, one aim of early intervention is to reduce the impact of that condition on both the child and his or her family — with the ultimate aim of improving the long term outcomes of both the child and the family. The extent to which this may be possible will likely depend on the type of condition or delay and the appropriateness of early intervention. There is evidence that early interventions directed at children with behaviour, social and academic

⁸² Heckman, J 2004 'Invest in the very young' In Tremblay, Barr & De V Peters (eds.) *Encyclopedia on Early Childhood Development*, Centre of Excellence for Early Childhood Development, Montreal. Available at: <http://www.excellenceearlychildhood.ca/documents/HeckmanANG.pdf>; Heckman J. and Masterov D. 2007 'The productivity argument for investing in young children' in *Review of Agricultural Economics* 29(3): 446–93; and Perry B 2002 'Childhood experience and the expression of genetic potential: what childhood neglect tells us about nature and nurture', in *Brain and Mind*, 3: 79–100; ⁸² Lynn A. Karoly, M. Rebecca Kilburn and Jill S. Cannon 2005, *Early Childhood Interventions: Prove Results, Future Promises*; W. Steven Barnett 1995, "Long-term effects of early childhood programs on cognitive and school outcomes", *The Future of Children*, 5(3): 22-50; Graham Allen MP 2011, *Early Intervention: The Next Steps*, An Independent Report to Her Majesty's Government.

⁸³ Lynn A. Karoly, M. Rebecca Kilburn and Jill S. Cannon 2005, *Early Childhood Interventions: Prove Results, Future Promises*, RAND Cooperation: Santa Monica; Janet Currie 2000, *Early Intervention Programs: What Do We Know?*, Report Number JCPR-WP-160, Joint Centre for Poverty Research; Janet Currie 2001, "Early Childhood Education Programs", *Journal of Economic Perceptions*, 15(2): 213-238.

development delays can be successful at improving long-term outcomes (described in 3 — *literature review*).

Deriving useful insights on the potential benefits of early intervention for children with a disability or developmental delay

The principle limitation identified to the application of a typical cost benefit or (standard) cost effectiveness assessment framework is the lack of detailed, comparable studies examining the impact of early intervention programs on children with developmental delay. As 3 — *literature review* observed, although several studies have assessed the benefits of early childhood interventions for children generally, there are relatively few studies that have assessed the benefits of early intervention *for children with disabilities and developmental delay*. Further, those studies that have examined interventions targeted at children with disabilities and developmental delay *have not reported on the medium-term or long-term outcomes for these children in a consistent, comparable manner*.

There are limited data available on the medium and longer term benefits arising from early intervention programs specifically targeting children with disabilities or developmental delay. Rather, studies examining the benefits of early intervention generally focus on programs targeting children considered 'at risk' due to socioeconomic factors.

An absence of detailed literature with respect to the benefits of early intervention for children with disabilities and developmental delay was recognised in a Cochrane Review by Mayo-Wilson, Montgomery and Dennis.⁸⁴ This review examined over 130 studies in more than twenty countries, each of which assessed programs that provided personal assistance in the form of individualised support for people living in the community by a paid assistant other than a healthcare professional for at least 20 hours per week (focused on children and adolescents). The limited nature of the available data was evident to the reviewers, who noted:

Research in this field is limited, though one related review provides some evidence of the effectiveness of personal assistance for children and

⁸⁴ Mayo-Wilson E, Montgomery P, Dennis JA. Personal assistance for children and adolescents (0-18) with both physical and intellectual impairments. Cochrane Database of Systematic Reviews 2008, Issue 3

adolescents with intellectual impairments. ... While advocates may support personal assistance for myriad reasons, this review demonstrates that further studies are required to determine which models of personal assistance are most effective and efficient for particular people.

Due to the limited directly applicable evidence on the likely potential benefits of early intervention programs targeted at children with developmental delay (other than for certain, specific disabilities and conditions, and then only over a limited benefit horizon) carrying out a standard CEA will not be practicable.

In spite of the absence of studies measuring the potential benefits of early childhood intervention programs for children with a disability or developmental delay, it is nevertheless possible to utilise existing research and apply it to this cohort.

The research conducted to date reports realised benefits from participation in early childhood intervention programs for children with intellectual, emotional and behavioural developmental delays. Children with disabilities will in many cases exhibit these types of developmental delay. It would therefore be reasonable to conclude that children with disabilities that exhibit intellectual, emotional and/or behavioural developmental delays may benefit from the application of proven early childhood intervention programs.

It is important to note that the potential benefits for children with disabilities suggested within this report apply *only* to the emotional, behavioural or intellectual developmental delay aspects of the disability. Identified benefits, as taken from the available research, should not be applied or extrapolated to components of the disability that do not fit within these categories of developmental delay.

For the purpose of this report, the aspects of developmental delay referred to are defined as follows:

- *Intellectual developmental delay* — is defined as delay when a child does not meet the expected goals by a certain age in areas such as self care, language and learning⁸⁵
- *Emotional developmental delay* — when a child fails to meet certain expected emotional developmental goals by a certain age. An example is

⁸⁵ <http://www.psychology-lexicon.com/cms/glossary/glossary-i/intellectual-delay.html>

when a baby learns to smile at their parent's face (expected at four months) ⁸⁶

- *Behavioural developmental delay* — when the child fails to meet expected behaviours for their age. An example is attention spans. A child between the ages of 6-8 should be expected to concentrate on a task for 15-20 minutes. If a child cannot focus or maintain attention for this length of time they could be considered as demonstrating a behavioural developmental delay.⁸⁷

Exhibit 10 outlines the reported benefits for intellectual, behavioural and emotional developmental delays associated with a selection of early intervention programs. Again, it should be noted that the programs detailed below are not specifically targeted at children with a disability or developmental delay.

The exhibit demonstrates that early intervention programs have been shown to improve outcomes for children (0-6 years) with respect to a number of indicators, including:

- reduction in the need for special education
- improved IQ
- reduced behavioural difficulties, as measured by a number of different scales (such as the Developmental Behavioural Checklist)
- reduction in the need for emotional or behavioural remediation

In short, these programs demonstrate long term improvements for children with intellectual, emotional and behavioural developmental delays compared to children who have not received intervention.

⁸⁶ Ibid.

⁸⁷ <http://www.livestrong.com/article/264922-warning-signs-of-developmental-behavioral-delays/> accessed 14/9/2011

Exhibit 10

Outcomes related to Development Delays				
Characteristic	Intellectual Development Delay	Emotional Development Delay	Behavioural Development Delay	Other
Program				
The Abecedarian Project	<p>Longitudinal studies have shown that at age 21, the mean IQ for participants in the Abecedarian project was 4.5 points higher than the control group (89.7 compared to 85.2)</p> <p>At age 15, only 12 per cent of the treatment group required special education services, compared to 48 per cent of the control group</p>			Only 14 per cent of participants reported being incarcerated compared to 21 per cent of the control group.
Perry Preschool	<p>Directly after the program concluded, the IQ of participants was 12 points higher than the control group's IQ. 67 per cent of the program participants had an IQ of approximately 90, compared to 28 per cent of the control group.</p> <p>At age 15, only 15 per cent of the treatment group required special education services, compared to 34 per cent of the control group</p>			

Outcomes related to Development Delays				
Characteristic	Intellectual Development Delay	Emotional Development Delay	Behavioural Development Delay	Other
Program				
The Chicago Child-Parent Centres	<p>Only 5.8 per cent of participants had ever occupied a specific learning disability placement, compared to 9.3 per cent of the control group.</p> <p>At age 15, 23 per cent of the treatment group required special education services, compared to 38 per cent of the control group</p>	<p>There was no difference between the treatment group and the control group in the incidence of placement in special education for an emotional or behaviour disorder.</p> <p>However, the mean number of years for time spent in an emotional or behavioural placement was smaller for the treatment group, 0.13 years compared to 0.976 years.</p>		<p>Only 13.3 per cent of participants reported being arrested for a felony crime compared to 17.8 per cent of the control group;</p>
The Nurse Family Partnership				<p>During the first two years of a child's life, children born to mothers who participated in the program had 80 per cent fewer confirmed incidences of child abuse and neglect compared to children in the control group.</p> <p>During their second year of life, children born to mothers who participated in the program were 32 per cent less likely to have visited the emergency room than the control group.</p> <p>Four years after the program had finished, women who had participated in the program had fewer subsequent pregnancies and were more likely to be employed than their counterparts in the control group.</p>

Outcomes related to Development Delays				
Characteristic	Intellectual Development Delay	Emotional Development Delay	Behavioural Development Delay	Other
Program				
The Incredible Years Parenting Program			Based on the Eyberg Test, the treatment group were rated 20 per cent lower (representing fewer behavioral programs) than the control group	
Optimum Growth Project	The Kindergarten Checklist contains 69 tasks grouped into four skill areas of motor skills, visual skills, auditory skills and environmental awareness. At age 6, the Kindergarten Checklist mean for the treatment group was 4.1 percentage points higher than for the control group (81.6 per cent compared to 77.5 per cent)	At age 2, the mental and motor skills of children were measured on the Bayley Scale of Infant Development. This scale is widely used to determine general development progress. Incidence of scoring below 100 on the Bayley Scale of Infant Development was only 2.11 per cent of the treatment group, compared to 18.86 per cent of the control group.		At age 6, there were no incidences of child abuse or neglect in the treatment group. In comparison, 14.3 per cent of the control group had experienced an incidence of child abuse or neglect
Signposts for Building Better Behaviour		The Development Behavioural Checklist (DBC) is designed to assess the difficult behaviour of children with disabilities. The pre-test mean for parents who participated in the group parent program on the DBC scale for a child's difficulties with social relationships was 4.9. The post-test mean was 4.4	The Parent Hassles Scale (PHS) Child Behaviour measures the daily hassles experienced by families of children with disabilities. Higher numbers reflect more behavioural difficulties. The PHS Child Behaviour pre-test mean for parents who participated in the group parent program was 75.9. The post-test mean was 67.8.	On the Depression Anxiety Stress Scale (DASS), before participating in the program, the mean score for mothers' stress level was 13.8. After the program, the mean was 10.6. On the DASS, before participating in the program, the mean score for fathers' stress level was 10.9. After the program, the mean was 8.7

Outcomes related to Development Delays				
Characteristic	Intellectual Development Delay	Emotional Development Delay	Behavioural Development Delay	Other
Program				
		The pre-test mean for parents who participated in the group parent program on the DBC scale for a child's difficulty with regard to self-absorption was 16.4. The post-test mean was 14.2.		

Source: KPMG analysis of literature describe in 3 — literature review

Further evidence of the benefits of early childhood intervention programs are outlined in exhibit 11. Exhibit 11 contains the reported net benefits and benefit-cost ratios that were collected for a range of early intervention programs by Washington State Institute for Public Policy.⁸⁸ Included early childhood intervention programs containing cost benefit analyses, consisted largely of pre-kindergarten education and child welfare/visitation programs. For the purpose of this report, KPMG focuses on the results of the pre education programs (see Exhibit 11). Benefits arising from home visitation and child welfare programs results are not examined as they do not fit the usual service delivery model of early childhood interventions. Most early childhood interventions, especially for those with disabilities, are centre based and conducted within groups.

⁸⁸Steve Aos, Roxanne Lieb, Jim Mayfield, Marma Miller, Annie Pennucci 2004, *Benefits and costs of prevention and early intervention programs for youths*, Olympia: Washington State Institute for Public Policy.

Exhibit 11 — Benefits and Costs of Selected Programs (2010 AUD Dollars)

Program	Benefits	Costs	Benefits per dollar of cost	Net Benefits
Pre-Kindergarten Education Programs				
Early Childhood Education for Low Income 3- and 4- Year Olds	\$32,089	\$14,224	\$2.26	\$17,865
HIPPY (Home Instruction Program for Preschool Youngsters)	\$6,180	\$3,579	\$1.73	\$2,601
Parents as Teachers	\$8,021	\$6,819	\$1.18	\$1,203
Parent-Child Home Program	\$0	\$7,578	\$0.00	-\$7,578
Even Start	\$0	\$9,474	\$0.00	-\$9,474
Early Head Start	\$8,894	\$40,857	\$0.22	-\$31,963

Source: Steve Aos, Roxanne Lieb, Jim Mayfield, Marma Miller, Annie Pennucci 2004, *Benefits and costs of prevention and early intervention programs for youths*, p.6

The Washington State Institute for Public Policy study estimated that the benefits arising from early intervention ranged from \$0 per child to up \$32,000. The types of benefits included within the study were limited to those for which the authors were able to estimate a monetary benefit – such as educational outcomes. Any benefits that could not be monetized were not included. Issacs points out that these excluded benefits might include improved quality of life during childhood, increased engagement in civic society as adults, and greater capacity for making informed decisions.⁸⁹

⁸⁹ Julia B. Isaacs, “Cost-effective investments in children” in the *Budgeting for National Priorities*, The Bookings Institute: Massachusetts January.

There is significant variation in the range of reported benefits (and net benefits) among the studies included, and the authors note that for each program area that was considered, there were interventions that were cost effective and others that were expensive and did not produce any benefits.

The study reporting the highest benefits was *early childhood education for low income three- and four- year olds*, which is an aggregate of the costs and benefits of numerous programs, including small-scale pilot studies and widespread programs. The aim of these programs was to enhance the preschool experiences for low-income children. Each program uses different educational approaches in an attempt to improve the likelihood of student success. The reported benefits per dollar spent for this program was \$2.26.

Although the programs and pilots included within *early childhood education for low income three- and four- year olds* were reported accrue significant net benefits, the *Even Start* program – which sought to improve the literacy of children through early childhood education, parenting education, adult education and parent-child joint literacy activities – was found to accrue no measurable benefits to the children involved. Both of these programs were aimed at low-income children and both used education to try and improve the children’s long-term outcomes.

That there is significant variance in the reported outcomes for early intervention among programs that applied similar interventions to similar groups of (low-income) children, necessitates a cautious approach when seeking to extrapolate results to different populations. Karoly et al. from the RAND Corporation suggest that the same early intervention program implemented under different conditions is unlikely to have the same effects. They argue that program effects are likely to vary due to numerous factors, including program design, the population served, and the local context in which the program is delivered.⁹⁰

An alternative cost effectiveness framework

As noted earlier, a key aim for this study is to examine the costs and benefits of expanding current Australian Government funding for early intervention

⁹⁰ Lynn A. Karoly, M. Rebecca Kilburn and Jill S. Cannon 2005, *Early Childhood Interventions: Prove Results, Future Promises*, RAND Cooperation: Santa Monica, p. xxii

services for children with a disability or developmental delay. It was not considered practical to apply a standard CEA framework to address this question. Although the data requirements for a CEA are less than for a cost-benefit analysis, the lack of detailed data addressing the potential benefits of different early intervention programs targeted at children with a disability or developmental delay meant that it was not possible to establish (within a CEA framework) robust counterfactuals to enable an assessment of the relative merits of different intervention approaches.

Instead, KPMG has:

- examined the range of benefits that have been shown to accrue to early intervention generally
- examined the extent to which certain conditions and recognised developmental delays exhibit symptoms that are consistent with the benefits that have been shown to accrue to early intervention – i.e. intellectual development, social development and emotional development
- estimated the potential number of children with these relevant conditions that may qualify for additional assistance to determine the potential cost to the Australian Government of extending the Better Start funding to these children, and
- considered the potential benefits that may accrue to children with the identified conditions, based on the presence in these children of particular developmental delays to which early intervention have been shown to improve outcomes.

The assessment of the range of benefits that have been shown to accrue to early intervention generally is set out earlier in this chapter. The remainder of the assessment is presented in 5 — *Applying principles of cost effectiveness to government policy*.

5 Applying principles of cost effectiveness to Government policy

After applying the framework outlined in 4 – *Cost Effectiveness – the broad issues*, to a range of potential conditions that could be considered for inclusion in the Better Start program, the assessment revealed that eight chromosomal conditions and Microcephaly are likely to cost the least, in terms of their incremental impact on Better Start (with the additional costs estimated to be in the order of \$3 to \$3.5 million per annum). Further, children with these conditions are also most likely to benefit from early intervention in terms of their intellectual development, social development and emotional development, as compared to other conditions that could be considered for inclusion.

Introduction

This section seeks to determine the cost effectiveness of expanding the Better Start program beyond the number of conditions it currently provides funding for. The process of selecting these conditions occurred in a number of different stages, which included:

- exclusion of conditions which would not benefit from early childhood intervention
- assessment of conditions against areas of benefit conferred by early childhood intervention programs, and
- assessing the program costs and indicative benefits of expanding this program to those conditions deemed to benefit from early childhood intervention programs.

Assessing the number of children in Australia with developmental delay

Several data sources were consulted in determining a reasonable estimate of the number of children in Australia (aged under six) with a developmental delay and/or disability. Key data that were examined included:

- The 2003 and 2009 Survey of Disabilities and Carers (SDAC) produced by the ABS⁹¹
- The 2006 Census⁹², and
- Centrelink data showing the number of carers receiving carer allowance, for children aged 0-6 with a diagnosed condition

The need to compare and collate data from a variety of sources is due to a number of reasons. For example, developmental delay can be due to a wide range of underlying conditions, which will be reported differently and (likely) inconsistently across data sources. Further, many conditions may not outwardly manifest in pre-school age children – such as learning difficulties, dyslexia and social develop delay – due to the absence of appropriate environmental stimuli against which a child's delay or condition may become

⁹¹ Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers* (2003, 2009).

⁹² Australian Bureau of Statistics, *Census of Population and Housing* (2006).

apparent. As such, general purpose surveys (such as the 2003 and 2009 SDAC) may systematically under-report the number of children with mild to moderate developmental delay and disabilities.

As at 2009, the total population of children aged 0-6, as recorded by the ABS, was 1,692,121. In 2009, the estimated number of children aged 0-4 with a reported disability was 47,300.⁹³ It should be noted that the 0-4 age cohort for which SDAC results are reported does not directly correlate to the early childhood intervention cohort of ages 0-6. However, if the percentage of children with a disability within the 0-6 cohort was equivalent to that observed for the 0-4 cohort (3.3 per cent), the total number of children with a disability in 2009 would be 50,763.

This estimate is consistent with Centrelink data for the total number of carers receiving a carer allowance for children aged 0-6 with disabilities. As at September 2010, Centrelink reported that 42,054 carers were receiving a carer allowance for a child 0-6 with a disability. This would suggest that of the children reported with a disability, 82 per cent of carers for those children receive a carer allowance.

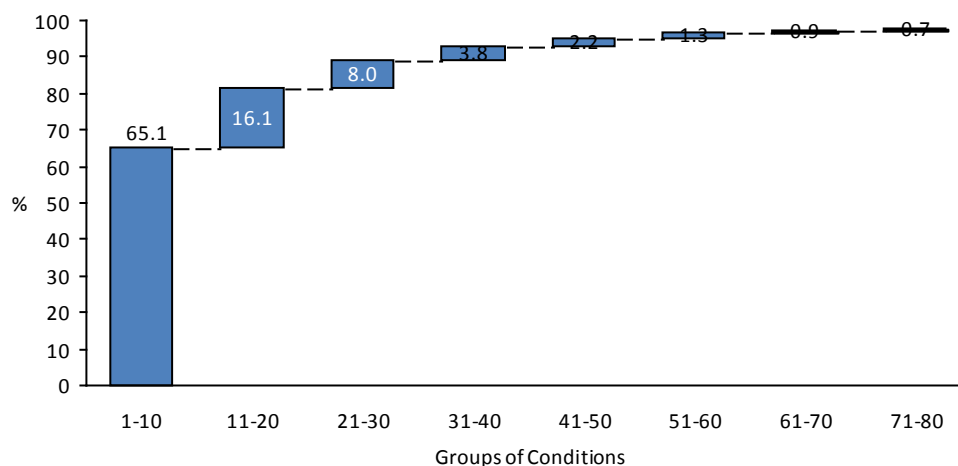
Reported conditions for children with a disability

In addition to providing a calibration for survey data, Centrelink data on the provision of carer support allows for a breakdown on the number of children under 6 with a disability or developmental delay *by condition*. Analysis throughout this section is based on the number of primary diagnoses only.

Currently, there are 275 conditions for which carers of children with a disability may receive a carer allowance. As can be seen in the following figure, although there are 275 registered conditions, these are highly skewed to a few prevalent conditions with many conditions have only a handful of registered allowance recipients. The following exhibit displays the percentage of carer allowances attributable to the 80 most common diagnoses, broken down into sets of 10.

⁹³ 2009 SDAC, Australian Bureau of statistics

Exhibit 12



Note: conditions beyond the first 80 (81 to 275) are not shown in the above chart as they account for less than 0.5% of carer recipients.

Source: 2009 SDAC, Australian Bureau of Statistics

As illustrated above, the ten conditions with the greatest number of attributable carer allowances constitute 65 per cent of the total number of carer allowances provided for children with a disability aged 0-6. The number of recipients for each of these conditions is shown in the following exhibit.

Exhibit 13 — Ten conditions with the highest number of attributable carer allowances

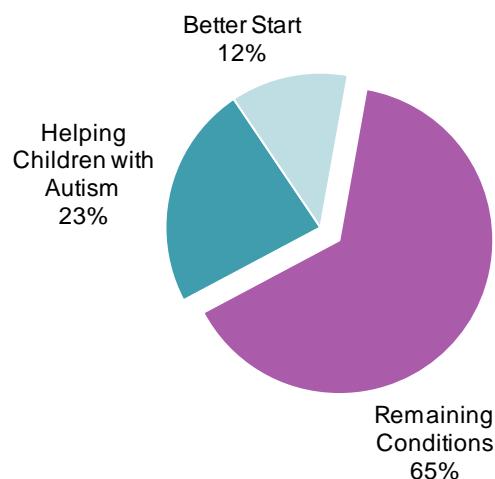
Condition	Total number of carer allowances (primary diagnosis)
Autistic disorder	8,389
Learning Disability	6,879
Speech disorder	3,170
Down Syndrome	1,524
Hearing Loss	1,487
Aspergers syndrome	1,370
Cerebral Palsy	1,339
Other chromosomal or syndromic condition	1,117
Asthma	1,075
Attention deficit/hyperactivity disorder	1,038

Source: Centrelink Carer Data, September 2010

After these first 10 conditions, the next twenty conditions with the highest attributable number of carer allowances constitute 24 per cent of the total number of carer allowances. This means that the 30 conditions with the highest number of attributable carer allowances constitute 89 per cent of the total number of carer allowances for children with a disability aged 0-6.

It should be noted that of these conditions some are already supported through FaHCSIA initiatives. Specifically children with Autistic disorder receive support through the *Helping Children with Autism* package, children with Down Syndrome, Hearing Loss and Cerebral Palsy are currently provided assistance through the *Better Start* initiative. Exhibit 14 distinguishes the proportion of registered allowance recipients currently receiving assistance within the *Better Start* and *Helping Children with Autism* initiatives.

Exhibit 14



Source: Centrelink Carer Data, September 2010

Analysis of conditions that may benefit from early childhood intervention

Given the long tail associated with the list of conditions eligible for carer allowances, for the purpose of this analysis the 100 conditions with the highest number of attributable carer allowances were assessed. Of these conditions:

- 10 conditions are already included in the Better Start program (NOTE: this includes duplications of hearing and vision related conditions), and

- Four are included in the Helping Children Living with Autism package⁹⁴

These conditions will not be included in this analysis. As illustrated above, these conditions constitute 35% of current carer allowance recipients.

In determining which conditions are most suitable for inclusion into the Better Start program (and therefore receive funding for early childhood intervention services), it is important to identify which of the current conditions receiving carer allowances may respond to early childhood intervention treatment programs.

To do so, each of the conditions must be assessed as to whether they consist of symptoms that will benefit from early childhood intervention services. As noted in chapter 4, available evidence on the effectiveness of early childhood intervention suggests that it is effective in improving outcomes related to intellectual, emotional and behavioural development.

Conditions that are therefore unlikely to be suitable for inclusion are conditions where treatment is provided primarily through medical intervention⁹⁵ (and/or classified as a medical condition under the List Of Recognised Disabilities (LORD)), or the condition is not sufficiently defined in the description to ascribe symptoms (for example, “other chromosomal or syndromic condition”).

Exhibit 15 outlines the number of conditions proposed for exclusion, and the reason why.

Exhibit 15

Reason for exclusion	Total number of conditions excluded
Treatment primarily through a medical model	64
Condition is not sufficiently described	5

Source: KPMG

Although not specifically excluded due to requiring treatment primarily through medical intervention, or though being insufficiently defined; epilepsy has been

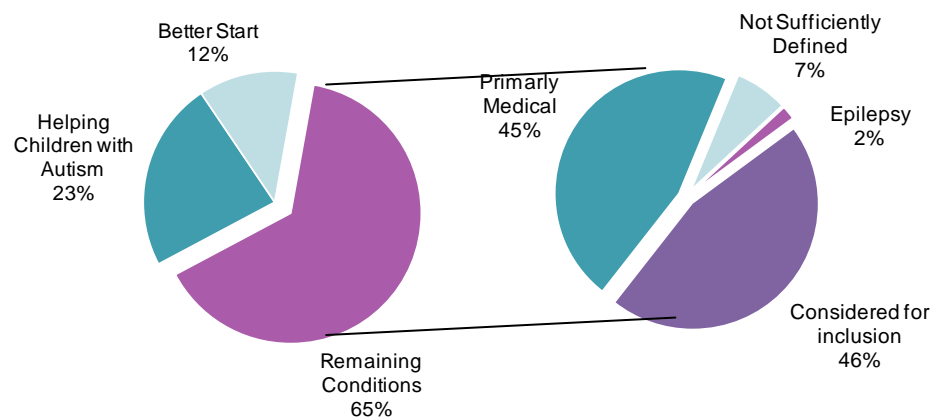
⁹⁴ The conditions are Autistic disorder, Asperger’s disorder, Rett’s disorder and Childhood Disintegrative Disorder

⁹⁵ i.e. the prescription of medication or therapies by medical professionals

deemed to be a special case for this analysis. It has been excluded from further analysis in this report as it has been assessed as benefitting primarily from medical interventions. However, it is noted that many children with epilepsy will also present with symptoms that will benefit from early intervention programs – for example, approximately 28 per cent of children with epilepsy will also have speech disorders.⁹⁶ In addition, approximately half of the children with epilepsy also display academic difficulties and/or behaviour disorders⁹⁷. It is therefore useful to note that epilepsy is a condition that may benefit from inclusion into the Better Start program, however this would require further investigation, due to the complexities relating to treatment, which are also compounded by the severity of the individual condition.

17 conditions remain after application of the exclusion process, which represent approximately 12,500 carer allowances (or 29 per cent of the total), illustrated below.

Exhibit 16



Source: Centrelink Carer Data, September 2010

⁹⁶ Kati Rantanen, Kai Eriksson and Pirkko Nieminen 2011, "Cognitive impairment in preschool children with epilepsy", *Epilepsia*, 58(8): 1499-1505.

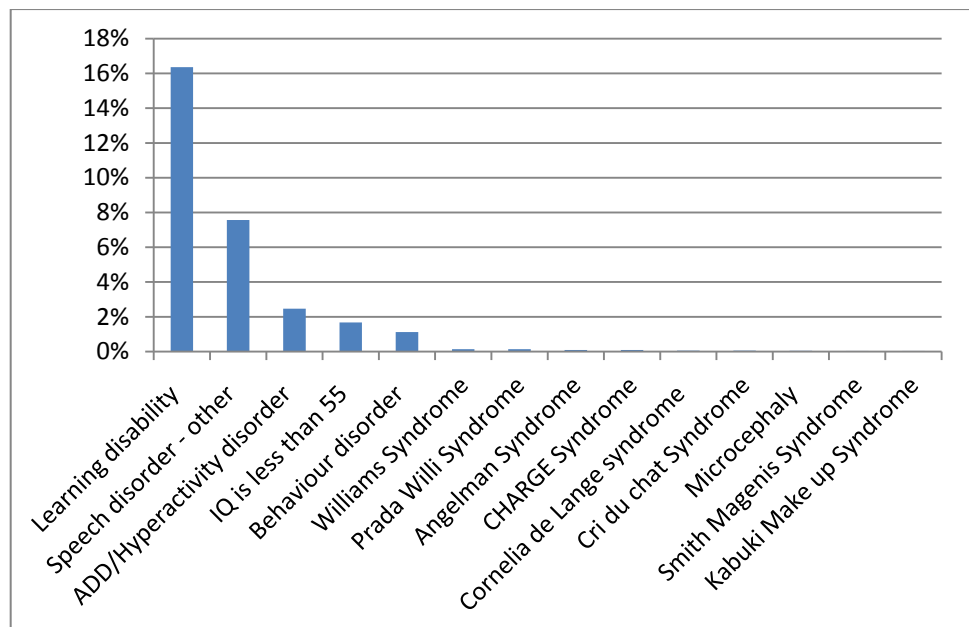
⁹⁷ M. Lassonde, H.C. Sauerwein, I. Jambaque, M.L. Smith, C. Helmstaedter 2000, "Neuropsychology of childhood epilepsy: pre- and postsurgical assessment", *Epileptic Disorders*, 2(1): 3-14.

Within these seventeen conditions, two conditions can be further consolidated. Speech Disorders are included twice, differentiated by severity. For the purposes of this analysis, Speech Disorder conditions will be considered once.

Obsessive Compulsive Disorder and Oppositional Defiant Disorder (both included in the final 17) are also to be removed. OCD and ODD are generally diagnosed in the later stages of childhood or early adolescence, and therefore obtaining reliable incidence and prevalence figures for application across the 0-6 age group (to allow further analysis) is not possible.

The final number of conditions is therefore 14. Exhibit 17 demonstrates the percentage of carer allowances received for each of the remaining diagnoses.

Exhibit 17



Source: Centrelink Carer Data, September 2010

Assessment of conditions for inclusion into the Better Start program

The conditions identified as requiring further assessment against early childhood intervention criteria are outlined in the exhibit below. The exhibit aligns the condition against whether or not it exhibits intellectual, emotional or behavioural developmental delay as part of its symptoms.

Exhibit 18

Characteristic	Development Delays		
	Intellectual	Emotional	Behavioural
Condition			
Learning disability	✓		
Speech disorder	✓		
ADD/Hyperactivity Disorder		✓	✓
IQ is less than 55			
Behaviour disorder		✓	✓
Williams Syndrome	✓	✓	✓
Prader-Willi Syndrome	✓	✓	✓
Angelman Syndrome	✓	✓	✓
CHARGE Association	✓	✓	✓
Cornelia de Lange Syndrome	✓	✓	✓
Cri du Chat Syndrome	✓	✓	✓
Microcephaly	✓	✓	✓
Smith-Magenis Syndrome	✓	✓	✓
Kabuki Syndrome	✓	✓	✓

Source: KPMG Analysis

Each of the conditions included in the above exhibit, its signs and symptoms are briefly described below. Incidence per live birth is also included, for determining prevalence of these conditions amongst the 0-6 age group.

Learning Disability

A learning disability can include numerous disorders. In effect, a child with a learning disability finds it extremely difficult without assistance, or is unable, to think, speak, read, write, spell or perform mathematical calculations at expected levels for his or her age.⁹⁸

Approximately four percent of Australian children have a specific learning disability.⁹⁹

Speech disorder

Most young children pronounce words differently and some words incorrectly. This is usually overcome by a certain age. If not, it is possible that a child has a speech disorder. Some speech disorders occur because a child has a physical problem, such as a cleft palate, which makes it difficult for them to formulate the sounds of speech. It is also possible that there is no specific reason for the speech disorder.¹⁰⁰

A development study in the UK compared a group of language-delayed infants, who were identified before their first birthday, who received treatment compared to a control group. Both groups were tested at age three– the usual age that children are referred for speech and language therapy – to determine whether there were differences in language development. At age three, 85 per cent of the control group showed a language development delay, compared to only five per cent of the treatment group.¹⁰¹ The outcomes of this early

⁹⁸ Anna Gemma, “Early intervention for preschool children with learning disabilities”, US Department of Education, 1988.

⁹⁹ “Schooling Issues Digest – Students with Learning Difficulties in Relation to Literacy and Numeracy”, *Australian Government Department of Education, Employment and Workplace Relations*, Available [online]:

http://www.dest.gov.au/sectors/school_education/publications_resources/schooling_issues_digest/schooling_issues_digest_learning_difficulties.htm#2

http://www.dest.gov.au/sectors/school_education/publications_resources/schooling_issues_digest/schooling_issues_digest_learning_difficulties.htm#2

¹⁰⁰ “Speech (sound) disorders”, *Raising Children Network*, Available [online]:

http://raisingchildren.net.au/articles/speech_disorders.html/context/510 [Accessed 12 September 2011]

¹⁰¹ Sally Ward, “An investigation into the effectiveness of an early intervention method for delayed language development in young children”, *International Journal of Language and Communication Disorders*, 34(3): 243–264

intervention program are significant as speech delays have been linked to longer term education difficulties, particularly with regard to reading.¹⁰²

Approximately 4 per cent of Australian children have a speech disorder.¹⁰³

IQ Less than 55

An IQ of less than 55 indicates very low IQ. 2 out of every 100 people have an IQ of less than 55.¹⁰⁴

Behavioural Disorder

Behavioural disorder is a broad category that is usually used to group a range of more specific disorders that exist.

It is likely that a child with a behavioural disorder would benefit from early intervention. Indeed, in a study conducted by Carolyn Webster-Stratton, it was concluded that children aged between two and six with conduct disorders whose parents participated in parent training programs had more significant improvements than older children.¹⁰⁵ However, behavioural disorder has not been included in further analysis in this report, as data does not exist about the prevalence of behavioural disorders in young children. This may be because the diagnoses of behavioural disorders often does not occur until a child reaches primary school.

Attention deficit hyperactivity disorder (ADHD)

ADHD is a behavioural disorder. The disorder does not affect a child's intellect. Children with the disorder often feel out of control. Typical behaviours associated with the disorder include difficulty concentrating, forgetting instructions, constant restlessness and fidgeting.

¹⁰²Pam Enderby and Joyce Emerson 1996, "Speech and language therapy: does it work?", *British Medical Journal*, 312(7047).; Aoife Lily Gallagher and Shula Chiat 2009, "Evaluation of speech and language therapy interventions for pre-school children with specific language impairment: a comparison of outcomes following specialist intensive, nursery-based and no intervention", *International Journal of Language and Communications Disorders*, 44(5): 616-638

¹⁰³"Speech (sound) disorders", *Raising Children Network*.

¹⁰⁴"How are scores on IQ tests calculated?", Available [online]: <http://psychology.about.com/od/psychologicaltesting/f/IQ-test-scores.htm>

¹⁰⁵Carolyn Webster-Stratton, "Preventing Conduct Problems in Head Start Children: Strengthening Parent Competencies,"

Approximately two to 5 per cent of children in Australia have ADHD.¹⁰⁶

Williams Syndrome

Williams syndrome is a chromosomal condition that is characterised by physical conditions as well as developmental delays and learning disabilities. Most individuals with Williams syndrome have mild to severe learning disabilities and cognitive challenges. Often, individuals demonstrate intellectual “strengths and weaknesses”. In other words, they tend to excel in some intellectual areas, while in other intellectual areas, they demonstrate significant difficulties.¹⁰⁷

Approximately, four in 100,000 people are born with William syndrome.

Prader-Willi Syndrome

Individuals with Prader-Willi Syndrome have an obsession with food and eating, poor muscle tone and balance, learning difficulties, lack of normal sexual development, emotional instability and lack of maturity.¹⁰⁸

It is predicted that one in 20,000 births have Prader-Willi syndrome.

Angelman Syndrome

Angelman syndrome is a rare chromosomal disorder that is characterised by intellectual disability, developmental delay, seizures and behavioural uniqueness. Individuals with Angelman often have no speech or minimal use of words. Receptive and non-verbal communication skills are more frequently demonstrated than verbal ones.¹⁰⁹

CHARGE Syndrome

CHARGE Syndrome is a genetic disorder. The letters in CHARGE stand for: Coloboma of the eye; Heart Defects; Atresia of the choanae; Retardation of growth and/or development; Genital and/or urinary abnormalities; and Ear

¹⁰⁶ Ibid.

¹⁰⁷ “What is Williams Syndrome”, *Williams Syndrome Association*, Available [online]: <http://www.williams-syndrome.org/what-is-williams-syndrome> [Accessed: 9 September 2011]

¹⁰⁸ “Prader-Willi Syndrome: A Brief Introduction”, *Prader-Willi Syndrome Association of Australia*, Available [online]: <http://www.pws.org.au/general.html> [Accessed: 9 September 2011]

¹⁰⁹ “What is AS?”, *Angelman Syndrome Association*, Available [online]: <http://www.angelmansyndrome.org/whatis.html> [Accessed: 9 September 2011]

abnormalities and deafness.¹¹⁰ These are the primary characteristics of CHARGE syndrome.

Cornelia de Lange Syndrome

Cornelia de Lange syndrome is a congenital syndrome in which there are numerous symptoms and/or behaviours. The majority of children diagnosed with Cornelia de Lange syndrome are intellectually delayed, with the degree ranging from mild to severe. Learning difficulties and speech delays are often evident. In addition, individuals with Cornelia de Lange syndrome may exhibit a number of behavioural problems such as self-injury, compulsive repetition, anxiety, attention deficit disorder and attention deficit hyperactivity disorder.¹¹¹

Cri du Chat Syndrome

Cri du Chat syndrome is a genetic disorder. The most distinctive characteristic of the disorder is a high-pitched, cat-like cry. Other characteristics include low birth weight and poor growth, severe cognitive, speech and motor delays, behavioural problems such as hyperactivity, aggression and severe temper tantrums.¹¹²

On average, one in 32,500 births have Cri du Chat syndrome.

Microcephaly

Microcephaly is a condition in which the circumference of the head is smaller than normal because the brain has not developed properly or has stopped growing. Some children who have Microcephaly will have normal intelligence. However, Microcephaly is generally linked to an accompanying syndrome, and many children have mental retardation, delayed motor functions and speech, facial distortions, dwarfism or short stature, hyperactivity, seizures, difficulties with coordination and balance.¹¹³

¹¹⁰ "About CHARGE", *The CHARGE Syndrome Foundation*, Available [online]: <http://www.chargesyndrome.org/about-charge.asp> [Accessed: 9 September 2011]

¹¹¹ Characteristics of CdLS, *CdLS Foundation*, Available [online]: <http://www.cdlsusa.org/what-is-cdls/characteristics-of-cdls.htm>

¹¹² "What is Cri Du Chat", *Support Group of Australia*, Available [online]: [http://www.criduchat.asn.au/criduchat/what.htm#Cri du Chat Syndrome](http://www.criduchat.asn.au/criduchat/what.htm#Cri%20du%20Chat%20Syndrome) [Accessed: 9 September 2011]

¹¹³ NINDS Microcephaly Information Page, *National Institute of Neurological Disorders and Stroke*, Available [online]: <http://www.ninds.nih.gov/disorders/microcephaly/microcephaly.htm> [Accessed: 12 September 2011]

Incidence for Microcephaly is approximately 1.02 per 10,000 births.¹¹⁴

Smith-Magenis Syndrome

Smith-Magenis Syndrome is a chromosomal disorder that is characterised by physical, behavioural and developmental difficulties. Common characteristics include infant feeding problems, developmental delay, mild to moderate mental retardation, early speech delay, hyperactivity and attention problems.¹¹⁵

Approximately one in 25,000 births have Smith-Magenis syndrome.

Kabuki Syndrome

Kabuki Syndrome is a rare genetic condition. Some characteristics that may appear in an individual with Kabuki Syndrome include abnormal facial feature, intellectual challenges, ranging from mild to moderate, and skeletal abnormalities.¹¹⁶

Approximately one in 32,000 births have Kabuki syndrome.

All of the above conditions are considered suitable for consideration for inclusion into the Better Start program. The following sections set out the likely indicative costs, and range of potential benefits from their inclusion.

Indicative estimates of condition incidence

Although the Centrelink carer data provides a view on the number of children in Australia with the conditions under consideration for inclusion in Better Start, it may not provide a reasonable estimate of the overall incidence. This is because the Centrelink data reflects only reported cases of these conditions. It is reasonable to expect that if a condition were to be included in Better Start (and hence eligible for additional funding) the incentives to diagnose a child with that condition may change.

¹¹⁴ "Prevalence of Microcephaly", Available [online]:

<http://www.rightdiagnosis.com/m/microcephaly/prevalence.htm><http://www.rightdiagnosis.com/m/microcephaly/prevalence.htm> [Accessed: 9 September 2011]

¹¹⁵ "What is SMS? Overview", *Parents and Researchers Interested in Smith-Magenis Syndrome*, Available [online]: <http://www.prisms.org/index.php/us/what-is-sms/overview> [Accessed: 9 September 2011]

¹¹⁶ "What is Kabuki Syndrome?", *Supporting Aussie Kids with Kabuki Syndrome*, Available [online]: <http://www.sakks.org/information/what-is-kabuki-syndrome.html> [Accessed: 9 September 2011]

In order to estimate the number of children in Australia that may have one of the identified conditions, KPMG has calculated a low-side and high-side range for the likely incidence of these conditions in Australian children aged 0-6, for 2006 to 2020 (Exhibit 19, below). This range has been calculated as 75 per cent (low-side) and 125 per cent (high-side) of the point estimates of condition incidence at birth to six years of age. These adjusted incidence rates have then been applied to ABS population estimates and forecasts for the cohort of children under six each year.

Exhibit 19

Year	Prada Willi Syndrome	Williams Syndrome	Angelman Syndrome	Kabuki Make Up Syndrome	Simth Magenis Syndrome	Cri de Chat syndrome	CHARGE syndrome	Cornelia de Lange syndrome	Microcephaly	ADHD	Speech disorders	Learning disabilities	IQ<55
2006	49-76	61-95	61- 95	38-60	49-76	38-30	78-123	80-126	121-189	36652-57269	54979-85904	48870-76359	2414-3771
2007	50-77	62-96	62-97	39-60	50-77	38-30	79-124	81-127	122-191	37152-58050	55728-87075	49536-77400	2443-3818
2008	51-79	63-98	63 -99	39-62	51-79	39-31	80-126	83-129	124-193	37905-59226	56857-88839	50540-78968	2477-3870
2009	51-80	64-100	64-101	40-63	51-80	40-32	82-128	84-132	126-197	38595-60305	57893-90458	51460-80407	2527-3948
2010	52-82	65-102	65-102	41-64	52-82	40-32	84-131	86-134	129-201	39189-61232	58783-91848	52251-81643	2573-4020
2011	53-83	66-103	66-103	41-64	53-83	41-33	85-133	87-136	131-204	39612-61894	59418-92841	52816-82525	2613-4082
2012	53-83	66-104	66-103	41-65	53-83	41-33	86-134	88-138	132-206	39726-62072	59589-93108	52968-82763	2641-4126
2013	53-83	67-104	66-103	41-65	53-83	41-33	86-134	88-138	132-207	39743-62099	59615-93148	52991-82799	2648-4138
2014	53-83	67-104	66-103	41-64	53-83	41-33	86-135	88-138	132-207	39628-61918	59442-92877	52837-82558	2650-4140
2015	53-82	66-104	66-103	41-64	53-82	41-32	86-134	88-138	132-206	39565-61821	59348-92732	52754-82428	2642-4128
2016	53-82	66-103	66-103	41-64	53-82	41-32	86-134	88-137	132-206	39520-61751	59281-92626	52694-82334	2638-4121
2017	53-82	66-103	66-103	41-64	53-82	40-32	86-134	88-137	132-206	39473-61676	59209-92515	52631-82235	2635-4117
2018	53 -82	66 - 103	66-103	41-64	53-82	40-32	86-134	88-137	132-206	39418-61590	59127-92385	52557-82120	2632-4112
2019	52 -82	66-103	66-102	41-64	52-82	40-32	85-133	88-137	131-205	39348-61481	59022-92221	52464-81975	2628-4106
2020	52-82	66-103	65-102	41-64	52-82	40-32	85-133	87-137	131-205	39256-61338	58885-92007	52342-81784	2623-4099

Source: KPMG analysis

Potential incremental costs from including proposed conditions in Better Start program

The Better Start program provides access to funding of up to \$12,000 (up to a maximum of \$6,000 per financial year) for early intervention services. KPMG has assumed that if one of the proposed conditions was included in the Better Start program, children with these conditions would be eligible to receive this funding. As such, the incremental cost to the Better Start program can be estimated by multiplying the per child funding allowance with the estimated prevalence of the particular condition in children under six.

Based on the estimated prevalence of the conditions assessed for inclusion in the Better Start program, there is a significant range in the annual incremental increases to the cost of the program from the inclusion of one or more of these conditions.

The following exhibit sets out the incremental costs to Better Start if the proposed conditions were included from 2012. These calculations are based on the low-side estimates of condition prevalence (that is 75 per cent of the point estimate of incidence in children 0-6). Note, the eight chromosomal conditions have been aggregated.

Exhibit 19 Incremental costs to Better Start from inclusion of particular conditions (\$, low-side incidence assumption)

	Chromosomal Conditions	Microcephaly	ADHD	Speech disorders	Learning disabilities	IQ<55
2012	2,436,000	792,000	238,356,000	357,534,000	317,808,000	15,846,000
2013	2,442,000	792,000	238,458,000	357,690,000	317,946,000	15,888,000
2014	2,442,000	792,000	237,768,000	356,652,000	317,022,000	15,900,000
2015	2,436,000	792,000	237,390,000	356,088,000	316,524,000	15,852,000
2016	2,436,000	792,000	237,120,000	355,686,000	316,164,000	15,828,000
2017	2,430,000	792,000	236,838,000	355,254,000	315,786,000	15,810,000
2018	2,430,000	792,000	236,508,000	354,762,000	315,342,000	15,792,000
2019	2,412,000	786,000	236,088,000	354,132,000	314,784,000	15,768,000
2020	2,406,000	786,000	235,536,000	353,310,000	314,052,000	15,738,000

Source: KPMG Analysis

It is clear from the exhibit that the incremental costs to the Better Start program would be far greater for certain conditions than for others. Combined, the incremental cost impact of including the eight chromosomal conditions would be in the order of \$2.5 million per annum from 2012 to 2020. On the other hand, inclusion of ADHD, speech disorders or learning disabilities, could result in incremental costs to Better Start more in excess of \$200 to \$300 million each year. This would more than *triple* the cost of the current program.

Potential benefits from including proposed conditions in Better Start program

As noted in chapter 4, there is a broad literature that suggests positive net benefits to early childhood intervention. Although there is an absence of literature specific to children with disabilities and developmental delay, there is reasonable evidence that early intervention can result in positive outcomes with respect to intellectual, social and emotional development.

As set out in exhibit 16 earlier in this chapter, the literature suggests that children with any of the eight chromosomal conditions, or Microcephaly are likely to exhibit intellectual development delay, social development delay and emotional development delay. That is, they are likely to exhibit delay in each of the domains that have been identified as being able to benefit from early intervention. Children with ADHD, learning disabilities, low IQ and speech disorders also experience developmental delay – but generally only with respect to their intellectual development (due to these conditions). As such, these children are unlikely to accrue the same range of benefits from early intervention as children with any of the eight chromosomal conditions, or Microcephaly.

Overall assessment

Taking the program costs and potential benefits into account, it is considered that the conditions most suitable for inclusion in the Better Start program are Chromosomal conditions and Microcephaly.

Chromosomal conditions and Microcephaly are likely to cost the least, in terms of their incremental impact on Better Start (with the additional costs estimated to be in the order of \$3 to \$3.5 million per annum). Further, children with these conditions are also most likely to benefit from early intervention in terms of

their intellectual development, social development and emotional development.

As children with the other conditions under consideration generally do not report social or emotional developmental delay (due to these conditions), it is unlikely that they would benefit from early intervention to the same extent. This is not say that children with the other conditions identified would not benefit from early intervention (and there may be positive net benefits per child for those receiving early intervention). However, the overall incremental cost to the Better Start program from including these children would raise significant issues. As noted above, inclusion of children with ADHD, learning disabilities or speech disorders could result in the costs of the Better Start program more than tripling.

Further, it is unlikely that effective early childhood intervention programs would be available for the number of children that may qualify for funding if ADHD, learning disabilities or speech disorders were included.

6 Bringing it all together

This chapter draws together the findings of this report by considering:

- Qualitative evidence from a review of research literature
- Quantitative evidence on the effectiveness of early childhood intervention programs
- The views of key stakeholders in the early childhood intervention field.

Overview

This report has discussed both the research literature on early childhood intervention and has used research on the effectiveness of specific interventions and programs to identify opportunities to refine Australian Government approaches to supporting children with a disability and their families.

The report has covered significant and diverse issues. This chapter considers the implications of these issues for government policy. It draws on two sources to deliver these conclusions. First, it describes the views of stakeholders consulted as part of the project. Second, it outlines KPMG's synthesis of its qualitative and quantitative analyses, in the literature review and economic analysis, respectively.

Stakeholder views

KPMG consulted with a select panel of early childhood intervention experts as part of its analysis for this project (see exhibit 21, below). The expertise of this panel helped KPMG draw together the issues identified in the qualitative and quantitative components of the project.

Exhibit 20 Names, positions and areas of expertise of stakeholders consulted as part of this project

Expert	Position	Area of expertise
Dr Tim Moore	Senior Research Fellow at the Centre for Community Child Health	Early childhood intervention literature and practice
Dr Rhonda Galbally	Chair of the National People with Disabilities and Carers Council	Disability sector and carer perspectives
Professor Greg Leigh	Royal Institute for Deaf and Blind Children; Member of the Better Start Expert Reference Group	Clinical effectiveness of interventions for sensory impairments
Associate Professor Michael Arthur-Kelly	Acting Deputy Head of School (Research Development) University of Newcastle	Early childhood intervention literature and practice
Professor Katrina Williams	APEX Australia Chair of Developmental Medicine, University of Melbourne Head, Department Developmental Medicine, Royal Children's Hospital	Expertise in a clinical effectiveness
Professor Elizabeth Elliott	Professor of Paediatrics and Child Health, Westmead Children's Hospital	Expertise in a clinical effectiveness
Trish Hanna	General Manager, Early Childhood Services, Learning Links, Sydney. Also a member of Early Childhood Intervention Australia	Service provider, family and carer perspectives
Susan Macgillycuddy	Service Manager, Kurrajong Early Childhood Intervention Service, Wagga Wagga	Early childhood intervention program effectiveness and practice
Stephanie Gotlib	Executive Officer, Children with Disability Australia	Family and carer perspectives
Ros Madden	Director, Australian ICF Disability and Rehabilitation Research Program	Assessment methods and characteristics

Source: KPMG consultations with key stakeholders

Assessment is central to the Australian Government's early childhood intervention programs. Stakeholders noted that:

- the current approach to assessment and determining eligibility is flawed
- a functional assessment would be both fairer and more consistent with research evidence

Three broad issues emerged in consultations with stakeholders. This section discusses each in turn.

Issue 1 — Assessment

Stakeholders observed that the current approach to determining eligibility for the Better Start initiative is inconsistent with a number of themes emerging from the research literature. First, and as 3 – *literature review* makes clear, a strong consensus is emerging on the value of tailoring interventions to the individual needs of children and families. In this regard, the current approach of the Better Start initiative, where eligible children and families are able to access a fixed value of support, does not tailor the *level* of support provided to individual child and family needs. However, stakeholders also observed that by giving families control over how their support is directed, Better Start does

allow for significant tailoring and personalisation of intervention strategies to families' circumstances.

Further, the diagnosis-based approach to assessment adopted by Better Start is, as outlined in 3 – *literature review*, based on a 'medical', or 'deficit' model. Stakeholders observed that a functional assessment that recognised children's and families' strengths as well as needs would provide a stronger basis on which to base intervention supports. While stakeholders uniformly supported the need for a functional assessment, they brought a range of arguments to support such an approach.

Stakeholders noted that while diagnosis-based assessments provide a transparent, easily-administered mechanism by which to determine eligibility, such an approach excludes a large number of families who may need support. Almost all of the stakeholders consulted observed that a significant number of children who require support do not have a diagnosis. In a system where the threshold for accessing support is a diagnosis, these children and their families are effectively excluded.

Building on the above, stakeholders also observed that an assessment system where a diagnosis is the driver for support creates incentives for families to overstate their support needs. A diagnostically-based system of assessment creates a situation where families seek out a diagnosis in order to become eligible for support, thereby emphasising their child's needs rather than strengths.

Stakeholders also observed that the diagnostically-based system of determining eligibility adopted by both the Better Start and Helping Children with Autism initiatives were effectively binary, and were insufficiently flexible or nuanced as a result. Such an approach effectively determines whether or not a child is eligible for support, and is therefore silent on the question of what kinds or levels of support a child and their family may need. On the basis of this logic, a number of stakeholders observed that it was impossible to determine whether the level of support provided under either the Better Start or Helping Children with Autism initiatives – both of which adopt a diagnostically based system of determining eligibility – was optimally effective.

Further, almost all stakeholders observed that many of the disabilities included in the eligibility criteria for both Better Start and HCWA can be conceived as a continuum. In this understanding of disability, a diagnosis-based approach legitimises a subjective determination (albeit by a highly trained professional) on where along that continuum a child's level of functioning lies.

While stakeholders identified challenges in the current approach to determining eligibility, they also acknowledged that alternative approaches may be difficult to implement, at least in the short to medium term. Stakeholders noted that an alternative approach to eligibility determination would most likely involve a functional or needs-based approach that recognised children's and families' strengths as well as needs. Functionally-based eligibility approaches have a number of advantages over diagnostically-based ones. For example, stakeholders observed that the process for obtaining a diagnosis can be complex, and can impose a significant cost on families – particularly those for whom a diagnosis is not straightforward. As a result, functional assessments allow for a more rapid and tailored response to child and family needs.

In addition, functional approaches to assessment and eligibility ideally involve a dialogue between a family and their service provider that allows each to tailor their mutual responsibilities to the evolving needs of families over a period of time. This approach has the advantage of customising support so that families can access only what they need, when they need it. On the basis of this logic, several stakeholders suggested that a system of functional assessment could realise efficiencies over the current approach.

While stakeholders noted the difficulties involved in establishing a functionally-based assessment mechanism for early childhood intervention, some did identify potential strategies for building functional assessment principles into the Better Start initiative. For example, one stakeholder observed that it may be possible to develop a graduated functional assessment for Better Start. Another observed that it may be possible to develop a hybrid system of assessment that incorporated both diagnostic and functional elements.

However, other stakeholders pointed to the opportunity that currently exists to build on the assessment infrastructure that would be developed as part of the implementation of a NDIS. Significant work remains to develop the

assessment methodologies and processes that would be required under a NDIS. There is a strong logic for investing effort in refining assessment for early childhood interventions – at both Commonwealth and state and territory levels – in a single, nationally consistent approach.

Stakeholders noted that a tension exists between improving the choice and intensity of ECI supports available to eligible families and broadening eligibility criteria to allow greater access to ECI supports for a larger number of children.

Issue 2 — Choice and access

Related to the issue of assessment, stakeholders also discussed the tension that exists between the breadth of coverage and choice of support provided by early childhood interventions. In effect, the current approach to assessment reflects an understanding of ECI as discrete services, rather than as supports that build families' skills in managing their needs. The tension identified by stakeholders pits two findings from the literature, outlined in *3 – literature review*, above.

Firstly, interventions delivered to a broad range of children responding to a variety of needs can have a small, positive impact on a large target population. As *3 – literature review* outlined, general interventions, such as quality early childhood education and care, can significantly improve children's social and economic participation, and can improve the functioning of children's families. This finding would support a view to improving access to ECI for a broad range of children.

Alternatively, and as *3 – literature review* also observed, targeted interventions that are delivered well to a defined cohort (such as a group of children with a specific condition or set of needs) can profoundly improve the skills and capabilities of a small number of children. This evidence would support the view that children with specific needs were supported through access to a *choice* of interventions of sufficient *intensity*.

This notwithstanding, this report considers *both* interventions that respond to children's needs *in a broad sense*, as well as those that respond to the needs of children and families with *specific needs* relating to a disability or developmental delay.

While a number of stakeholders recognised that a trade-off between access and program intensity exists, they differed in their approaches to resolving this tension. However, two themes did emerge in stakeholders' responses to this issue, relating to choice and access.

Choice

A number of stakeholders noted the importance of choice in the funding approach adopted for the Better Start initiative. For example, stakeholders noted that the capacity for families to direct their support allowances flexibly as they saw fit significantly added to families' control over the supports they are able to access. However, a number of stakeholders also observed that giving families control over their support funding contributed to the sense of 'chaos' that some families felt regarding their engagement with the ECI system.

Further, stakeholders observed that the role of identifying appropriate support amounted to families acting as a broker in performing complex, professional roles.

Consequently, stakeholders noted that while the funding approach under Better Start enhanced families' choice in accessing services, additional choice was only effective if it was accompanied by support designed to help families understand the choices open to them.

Stakeholders also identified an increase in the number of providers able to deliver ECI under Better Start, but had not observed an improvement in the perceived quality of service providers to meet additional demand.

Consequently, stakeholders questioned the reality of choice.

Finally, stakeholders observed that many families are supported to exercise their increased choice by services that are funded by state and territory ECI funding. Many of the services with whom families engage to help them make decisions about how they will use funding from Better Start or HCWA are not funded under those programs.

Access

All stakeholders raised the issue of access to ECI. However all recognised that access is a complex issue, and is particularly difficult to reconcile with constrained budgetary conditions across governments at present. At a high level, stakeholders noted that increasing access to ECI supports for a broader range of children was equitable.

However, other stakeholders were more equivocal in reconciling their desire to increase access to ECI supports, with the reality of managing resources sustainably.

One issue that adds to the complexity in weighing the breadth of access against the intensity of support in early childhood intervention is the degree to which ECI is increasingly used to support children with very complex needs and their families. To the extent that ECI is focused on delivering disability service outcomes for a number of children, it may be less able to achieve broader 'early intervention' outcomes for children with less – medically or contextually – complex needs. For this reason, it is important that the purpose and objectives of ECI are clear. To make the most effective use of limited resources, it is critical to first understand what 'effectiveness' means.

Stakeholders observed that the current Australian Government approach to supporting children under the HCWA package and Better Start initiative increases the complexity for eligible families. Significant opportunities exist to streamline the parallel ECI processes in place across the state and territory and Australian Government systems.

Issue 3 — Coordination and streamlining

This chapter has discussed the significant choice that the model of funding under Better Start has created for families. It has also described the complexity that exercising that choice can involve. This section describes that complexity further, and summarises stakeholder views on how families might be better supported to navigate the Better Start systems in the context of other ECI systems that also exist.

As outlined in *2 – project context*, both the Australian Government and state and territory governments support children with a developmental disability and their families through parallel early childhood intervention systems. In addition to the flexible funding provided to eligible families under the Better Start initiative and the *Helping children with Autism* program, state and territory governments provide broader support through specialist service providers. Stakeholders observed, however, that the combination of funding sources adds significant complexity to families' lives.

To lessen the sense of 'chaos' in families' lives, stakeholders highlighted a gap that currently exists for coordination of support for children and families, organised at the local level. Such coordination would help families to identify support and maximize the impact of funding, irrespective of its source. Stakeholders observed that this approach to coordination would provide a sense of coherence to families, and reduce the sense of their experiences of

early intervention being disjointed. Coordination is critical for improving outcomes for both children and families, since reducing the complexity that families of children with a developmental disability experience is in fact one of the key objectives of early childhood intervention.

In addition, stakeholders suggested that, as long as it was locally-based, coordination would enhance the capacity for ECI to take advantage of local linkages between universal services (such as early childhood education and care and maternal and child health), secondary services (such as early intervention services, community health services and family services) and tertiary services (such as 'acute' early interventions, acute medical services and child protection interventions).

Considering these issues within the current policy context

As was noted in *1 – project context*, the Productivity Commission is currently investigating options for the establishment of a NDIS. While the Commission has outlined some details of the proposed scheme in its draft report, significant uncertainty remains about key features of an NDIS and its operations. Critically, the Australian Government has not yet committed to the NDIS, although it has given in-principle support to the general proposition of significantly reforming the provision of disability services in Australia in the ways in which the Commission outlines.

However, and as a number of stakeholders observed, it is prudent to consider refinements to the Australian Government's support for early childhood intervention in the context of the possible introduction of an NDIS. In particular, the proposed approach for delivering support for people with a disability under the NDIS is similar in many ways to the one adopted under Better Start — that is, giving individuals (or, in the case of children with disabilities, families) control over their decisions regarding support options through flexible funding and a strong, competitive market of quality support providers.

Stakeholders also observed that the NDIS may provide a mechanism by which to resolve the issues relating to the introduction of a functional assessment in determining eligibility for support. The Productivity Commission's report introduces the concept of a functional assessment in its discussion of a

Many of the issues raised in this report are also issues that will be considered during the development of the NDIS. In particular:

- developing appropriate functional assessment approaches
- enhancing the coordination of support for families at a local level

Consequently, it is desirable for reforms to Australian Government early childhood intervention programs to build on the work and resources that will be invested in the NDIS's development.

proposed approach to determining eligibility, however, it also notes that developing such an approach would require significant work over a long period of time.¹¹⁷ For this reason, it may be possible for programs such as Better Start to build on the infrastructure that would be developed to support a functional assessment approach under the NDIS.

Alternatively, it may be possible to incorporate early childhood intervention approaches into the NDIS at an early stage of the scheme's development. Because of the similarities between the model of support under the proposed NDIS and the Better Start program, it may be possible to use early childhood intervention to pilot and refine the NDIS in its early implementation stages.

Further, and as 3 – *literature review* highlighted, there are substantial linkages between ECI and other services targeted to children, including those provided in the maternal and child health, early childhood education and care, community health and child protection systems. An opportunity exists for ECI to leverage off those linkages.

In particular, the reforms currently being progressed by the Council of Australian Governments across a broad range of early childhood services through the *National Partnership Agreement on Early Childhood Education*, the *National Partnership Agreement on the National Quality Agenda for Early Childhood Education and Care* and the *National Partnership Agreement on Indigenous Early Childhood Development* provide a framework and policy direction for greater integration of a range of services for children and families. Given this focus, there are opportunities for ECI to build on momentum across the early childhood policy.

Conditional options going forward

Because of the significant uncertainties in the early childhood intervention policy context, KPMG has identified three sets of conditional options for moving forward.

Conditional option 1 (below) proposes incremental refinements of the Australian Government's existing approach, building on both the literature review and the economic analysis of the effectiveness of specific programs.

¹¹⁷ Productivity Commission 2011 *Disability Care and Support*, Productivity Commission Report n. 54, Productivity Commission, Canberra.

The Australian Government should consider conditional option 1 if it wishes to retain the existing infrastructure for determining eligibility under Better Start, while expanding the range of conditions on which eligibility is determined.

Conditional option 1

Conditional option 1 — Incremental refinement of existing Australian Government support for early childhood intervention

This option would incrementally refine the eligibility criteria for Better Start by adding a limited number of additional conditions for which there is evidence of the effectiveness of interventions. As discussed in section 5 – *implications for government policy*, taking the program costs and potential benefits into account, it is considered that the conditions most suitable for inclusion in the Better Start program are Chromosomal conditions (including Prader Willi Syndrome; Williams Syndrome; Angelman Syndrome; Kabuki Make Up Syndrome; Smith Magenis Syndrome; Cri du Chat syndrome; CHARGE syndrome; and Cornelia de Lange syndrome) and Microcephaly.

Chromosomal conditions and Microcephaly are likely to cost the least, in terms of their incremental impact on Better Start (with the additional costs estimated to be in the order of \$3 to \$3.5 million per annum). Further, children with these conditions are also most likely to benefit from early intervention in terms of their intellectual development, social development and emotional development.

Expanding the Better Start eligibility criteria to include these conditions would increase the number of children and families able to access evidence-based early childhood intervention supports.

Source: KPMG analysis

Conditional option 2 (below) describes work to streamline the support provided by the Australian Government and state and territory governments for children with a disability and their families. The Australian Government should consider conditional option 2 if it wishes to respond to the evidence in the research literature on the value of streamlining support for children with a disability and their families through establishing more integrated, coherent pathways into ECI across the spectrum of early childhood services available through

providers funded by both the Australian Government and state and territory governments.

Conditional option 2

Conditional option 2 — Building stronger linkages for children and families across early childhood services

As outlined earlier in this chapter, overlaps in the roles of the Australian and state and territory governments have the potential to add complexity to the lives of children and families accessing ECI. An opportunity exists for the Australian Government and the state and territory governments to contribute to improving the overall accessibility and coordination of the ECI service system.

Reflecting this, conditional option 2 would see the Australian Government working closely with state and territory governments to link families more closely with appropriate services in both universal and specialist service settings. Under this option, the Australian Government would – with the cooperation of state and territory agencies responsible for ECI services – improve the understanding of and coordination between Better Start and other ECI services for families. In particular, work should be undertaken to specifically identify opportunities for Better Start to complement existing state and territory ECI systems.

Both the Australian Government and the various state and territory governments recognise the potential for better alignment and integration of ECI service systems. To this end, FaHCSIA has recently had some preliminary discussions with the Victorian Government Department of Education and Early Childhood Development about jointly undertaking work to develop principles and strategies that would ensure that the Better Start initiative meets its intended aim of complementing the Victorian Government's role in its ECI service system. This work could be progressed and expanded through the Better Start State and Territory Working Group.

As such, this option would require the Australian Government to work closely with state and territory governments to improve linkages between families and appropriate services and supports – whether they are state and territory-based ECI services, services funded through Better Start or other early childhood

services. This option would enhance the ‘reach’ of existing ECI service infrastructure and investment – across both levels of government – by leveraging infrastructure and investment from a variety of early childhood services and systems. This option could also be expected to help streamline the ECI experience for a broad group of families and responds directly to the evidence outlined in 3 – *literature review* on the efficacy of universally-based interventions for children with a wide range of vulnerabilities.

This option would help to integrate ECI supports from the perspective of children and families. Integration is a key theme in the broader early childhood reforms being progressed by the Council of Australian Governments, discussed earlier. As such, in developing this option, the Australian Government should explore opportunities for reform in relation to ECI to build on reforms in other areas of early childhood development.

Additional work is required to further refine the Australian Government’s role under this option – in consultation with key stakeholders and across Australian and state and territory governments – building on the evidence outlined in this report and elsewhere.

Source: KPMG analysis

Conditional option 3 (below) describes more extensive reform of early intervention nationally in the context of the broader development of a National Disability Insurance Scheme. The Australian Government should consider conditional option 3 if it wishes to leverage the possible introduction of an NDIS to significantly reform its support for ECI.

Conditional option 3

Conditional option 3 — Working with the proposed NDIS to substantively reform early childhood intervention nationally

Under this option, the Australian Government would – in the event of an NDIS being established – work with state and territory governments through the Council of Australian Governments and the taskforce charged with implementing the NDIS to identify early childhood intervention as a priority for the NDIS’s early implementation. There is a strong logic in linking current early childhood intervention supports to the NDIS, since such links would significantly streamline families’ experiences of interventions – particularly for

those families accessing supports from both the Commonwealth and state and territory systems.

Linking with the NDIS would allow the Australian Government to leverage the likely investments in establishing the NDIS infrastructure — including a nationally-consistent assessment methodology and framework for coordinating support at the local level — to refine the current approaches of the HCWA package and Better Start initiative.

Implementing a nationally-consistent framework for functional assessments is a significant challenge that will require significant work from government agencies, academic experts and ECI professionals. The investment of time and resources required to establish such a framework is out of proportion with the size of the sector in which it would be implemented. Consequently, a more sustainable and pragmatic approach would be to build on work to establish a functional assessment framework across both the paediatric and adult disability sectors nationally.

The NDIS as proposed would promote local area coordination and development¹¹⁸ to improve the coherence of the intervention experience for families at the local level. As 3 – *literature review* observed, coordination for families is a significant gap across both state and territory and Australian Government ECI service systems. Linking with the NDIS would provide a mechanism to substantially resolve these issues.

Improving outcomes for children with a disability and their families in the way that 5 — *implications for government policy* outlines requires more significant and coordinated effort both across Australian Government departments, and across levels of government. For example, improving year 12 completion rates for young people with a disability will require collaboration not only between FaHCSIA and DEEWR, but also between the Australian Government and state and territory governments.

However, there are significant potential benefits for the Australian Government in working with state and territory governments to improve outcomes from investments in early intervention. For example, the Australian Government

¹¹⁸ Productivity Commission 2011 *Disability Care and Support*, Productivity Commission Report n. 54, Productivity Commission, Canberra.

would benefit from any reforms that improve the labour force participation of people with a disability. For every dollar state and territory governments collect in taxation as a result of improved disability outcomes leading to increased employment, the Australian Government collects almost six dollars.¹¹⁹ The Australian Government is also likely to benefit from improved outcomes for children with a disability that result in lower need for Disability Support Payments and Carer Payments.

As a result, it is in the Australian Government's interests to work with state and territory governments to improve outcomes for children with a disability and their families. The NDIS provides a mechanism by which the Australian Government could significantly progress transformational reform in early childhood intervention.

Source: KPMG analysis

¹¹⁹ Australian Bureau of Statistics (ABS) 2007, *Government Finance Statistics, Australia, 2005-06*, cat. no. 5512.0.

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