Submission in response to the Productivity Commission

Disability Care and Support Issues Paper

Early Childhood Intervention Australia (National)

August 2010

1. Summary and Recommendations

1.1 General

Early Childhood Intervention Australia (ECIA) supports the introduction of a Disability Insurance Scheme. Such a Scheme should promote the development and participation of children with disabilities through the provision of appropriate supports and services based on individual needs, citizenship and human rights. While ECIA recognises the needs of all people with a disability, and believes all people with a disability should benefit from such a scheme, its expertise and focus is on young children.

Who should benefit from the Scheme?

1. The underlying basis of eligibility for a scheme should be need and not medical diagnosis. Many young children with disabilities and developmental delays do not have formal diagnoses. Eligibility should be based on need regardless of how the disability was caused or the age it was identified.

What principles should underpin the scheme?

2. The provision of support needs to recognise that each child is unique and all families have unique cultural, socioeconomic, geographic and linguistic characteristics.
3. The provision of support needs to recognise that the outcomes that we are seeking for children with disabilities are consistent with the outcomes we are seeking for all children.
4. The provision of support needs to be through a simple eligibility process that creates access to services for the child, the family and within community settings.

What should the scope of the scheme be?

5. The scheme should have a holistic view that recognises that disability does not only affect an individual, but also the whole family. It should support the education and development of the child and the social participation of the child and his or her family.
6. The scheme should be integrated with services for young children and families ensuring full participation.
7. The scheme should recognise the individual needs of children and families and be structured to ensure consist support as children make transitions to new stages and experiences and as circumstances change.
8. The scheme should have a whole of life approach, recognising and the growing independence of young people.
9. A scheme should be flexible and responsive to changing needs and maintaining both the child’s development and participation.
10. The scheme should recognise that for many families having a child with a disability involves significant additional costs including modification to housing and lost employment opportunities.
11. The scheme should be funded via a levy similar to the Medicare Levy.
12. The scheme should be administered by a government agency specifically established for the purpose.
13. The scheme should include features such as a concession card and a companion card.
14. The scheme should be provided in the same way nationally.

15. Eligibility to the scheme should be national.
16. Information about the scheme should be provided to all people with disabilities and their families in an appropriate way.
17. The governance of the scheme should include people with disabilities and their carers.
18. The administration of the scheme should be transparent.

2. Introduction

The provision of appropriate supports and services for young children with disabilities and their families has personal benefits and potential longer term savings from improved educational outcomes, better labour market participation, reduced dependence on public assistance and lower levels of criminal activity.

Access to timely and adequate early childhood intervention (ECI) has been demonstrated to improve outcomes for children with developmental delays and disabilities and their families. Unlike some other countries, including the USA, in Australia there is no right to a service following identification of a disability. In some jurisdictions families can wait up to two years for access to a service for their child.

The current level of services for young children with disabilities and developmental delays is inadequate and demand is growing. Delays in accessing effective assistance result in:

- Lost opportunities to minimise the effects of disability resulting in distress, unnecessary ongoing dependency and more costly services throughout life;
- Lost opportunities for families to provide optimal family life due to poor mental health, family distress and breakdown;
- Lost opportunities for children with disabilities to benefit from greater participation in quality, universal early childhood education and care setting, sharing enjoyment and play, making friends, learning with others and achieving alongside their peers.

Whilst current services are provided by highly trained professionals who can provide flexible services, the amount and variety of support needed cannot be provided with current funding regimes. Early childhood intervention professionals are currently under extreme pressure to adequately support children with developmental delays and disabilities and their families within significant funding constraints. Current funding regimes do not recognise the complexity of children's needs, the needs of their families and children's needs in mainstream children's services.

Numerous Government reports have identified deficiencies in the early childhood intervention system. Whilst Governments have expressed a commitment to giving children with developmental delays and disabilities the best possible start to life, the following issues are yet to be addressed:

- Too many children are waiting too long: Children with developmental delays and disabilities are experiencing significant delays in accessing early childhood intervention and are missing out on potentially beneficial intervention and support during a key development stage.
- Families do not get the support they need: some families caring for children with disabilities are experiencing chronic stress from the care-giving and emotional demands of learning about and adapting to their child's disabilities and navigating the complex service system that is meant to help them.

- Lack of capacity for universal services to respond to the needs of children with developmental delays and disabilities: the assumption that early childhood intervention services can (or should) meet all the needs of children with disabilities and developmental delays and their families is resulting in inadequate responses by universal services such as child care and preschool.

3. About Early Childhood Intervention Australia (ECIA)

ECIA provides a national focus and forum, promotes the public profile of Early Childhood Intervention, facilitates effective liaison and advocacy in the community, and fosters quality information and service provision. Services include organisation of seminars and workshops and a national conference every two years.

Early childhood intervention is the process of providing specialised support and services for infants and young children with developmental delays or disabilities, and their families in order to promote development, well-being and community participation.

ECIA has a Chapter in each state and territory. A National Council coordinates activities across Australia with two representatives from each Chapter.

4. Human Rights

The United Nations Convention on the Rights of The Child (1989) provides an image of children as subjects of rights and full members of society, capable of participating in their social worlds through their relationship with others. These principles are consistent with current early childhood research. These rights are currently not afforded to young children with disabilities due to a lack of appropriate support.

5. Discussion of Specific Issues

5.1 Who should be the key focus of a new scheme?

The scheme should be open to all children with a disability or developmental delay. In recognition of the high costs of living with a disability for families and children it should not be means tested.

Support for children with disabilities should not be dependent upon diagnosis. Many children do not receive a diagnosis for some time, or may never receive a diagnosis. Support should be provided equitably on the basis of individual needs as significant developmental issues and delays are identified. Immediate access to support is the underlying premise of ‘early intervention’. Disability and developmental delays impact on children in profoundly different ways, including intellectual, physical and social development. The severity of different conditions varies significantly. Responses need to be individualised and based on improving the child’s functional development and ability to participate meaningfully. Some conditions will involve episodic peaks in support needs. Some conditions are degenerative and will lead to increasing needs.

Services for young children and their families need a radical overhaul. Currently different tiers of government and different departments apply different eligibility requirements. Families must apply for different supports with different eligibility for early childhood intervention, child care, preschool, school, aids and equipment, respite, home care to name only some programs. This system is described as a maze by parents and is very time consuming and costly to administer.

The provision of programs by both the State and Commonwealth has contributed to significant confusion and an added burden on families, as these programs are not at all integrated.

5.2 What kinds of services need to be increased or created?

Children

Children can't wait. The services provided are not consistent across Australia. In some jurisdictions there are a finite number of places which is less than demand and this has led to waiting periods of up to two years. This situation needs to be addressed urgently. Children need access to educationally appropriate programs as soon as delays or issues are identified.

Families

A lack of support to care for their child with a disability can be detrimental to the emotional wellbeing of family members and the development of the child. Every child's development is dependent on the learning opportunities and experiences provided by their family.

- Families need access to emotional support to assist through the adjustment period of having a child with additional needs and the grieving process which often accompanies this.
- Families need support to manage the additional pressures to make necessary adaptations and access community supports.
- Families need assistance to navigate the maze of services/funding provided by different jurisdictions (local, state and federal governments), gain information and advice when it is needed; and develop the skills to become advocates for their child's needs.
- Families need assistance to build positive relationships with their children and develop the skills needed to meet their child's developmental needs. Only families can provide children with the secure foundations they need to develop to their potential.
- Families need access to resources to support the wellbeing of the whole family so that the demands made by caring for a child with a disability do not lead to family breakdowns, illnesses or socioeconomic disadvantage.

Children's Services

Children with developmental delays/disabilities need the same opportunities to actively participate in universal early childhood programs, such as child care and preschool and to meet early childhood outcomes. The importance of education during the early years is internationally recognised. Measures need to be taken to ensure children with disabilities and developmental delays fully benefit.

Professional support for children's services staff

Unlike their typical peers, children with disabilities will not benefit fully from attending child care and preschool unless staff understand their abilities. Staff rely on visiting early childhood intervention practitioners and other consultants to provide information about individual children. Currently, these practitioners are only able to visit children's services on a very limited basis. This needs to significantly increase.

With increased skills, confidence and knowledge, children's services are more likely to welcome children with developmental delays and disabilities into their programs and increase opportunities for parents to return to the workforce.

Some children with disabilities need additional staff support to attend child care or preschool

Currently this is often not available for the whole time the service is open. This can lead to limited access or exclusion from these services. When additional staff are necessary, this should allow children to access the whole program. If children do not access the whole program their educational outcomes are compromised.

5.3 What are the ways of achieving early intervention?

The development of the services for young children with disabilities should be treated with the same level of concern as the development of educational and health services for all children. The development of educational and health services for all children are supported by significant public investment in research and the translation of research to practice. The development of paediatric services for children with disabilities is a complex and highly responsible task. It is possible to be ineffective or to do harm. Australian authorities have not recognised the seriousness of this task. Leaving the provision of service to market forces without professional scrutiny is not acceptable for the education and health services provided to the general population of children. It should not be considered appropriate for children with disabilities and developmental delays.

5.4 How could a new scheme encourage the full participation by people with disability and their carers in the community?

The scheme needs t recognise that disability is complex and responses need to consider:

- the individual child
- the child's family
- the community they live in and services they use.

5.5 How can people with disabilities or their carers be given more power to make their own decisions?

People with disabilities and families have the right to actively participate in all processes which affect their lives and should have the opportunity to participate in transparent administrative processes. Information must be made available recognising a range of communication needs and this may necessitate providing information in a variety of formats that recognise both individuals capabilities and cultural backgrounds.

5.6 How can coordination, costs, timeliness and other aspects of service delivery improved and innovation encouraged?

The rationalisation of eligibility criteria would have a major impact on families, creating certainty and removing an onerous administration burden.

5.7 How much support should people get and who decides this?

The guiding principle for the provision of support should be that the individual child with a disability has the supports needed to pursue the developmental and participatory outcomes common to all children and that families have the resources needed to both support the child with a disabilities development and maintain the wellbeing of all its members.

5.8 How can any good aspects of current approaches be preserved?

There needs to be close cooperation across tiers of government to ensure services are integrated. The simplification of the eligibility process is key to ensuring current services can be accessed in an easy fashion. It would be helpful if one administration agency was given responsibility for ensuring an integrated approach to service delivery. The lack of anyone responsible is a key problem currently.

5.9 What can be done to improve rural and remote services?

Strategies to address rural and remote areas include incentives for professionals to locate in these areas and the development of virtual services.

5.10 What are the practical aspects of a scheme that will make it work?

While the essence of this submission relates to young children and their families, it is recognised that disabilities rarely abate. The underlying principle in moving from a ‘medical model’ to a ‘social model’ of disability is that a sole focus on cure is unhelpful, whereas adaptation and participation is helpful. In its focus on young children this submission emphases the importance of the best start. What happens next, and thereafter, is something a scheme must accommodate.

An underlying principle would be to promote independence and ensure people live a full life. To achieve this they need support where necessary to ensure access to employment, housing, information, education and social participation. Access to health, justice, education are not disability issues but rather human rights issues, and should be accessible to all. People with disabilities may need support to ensure their meaningful participation.

The right to an education that leads to meaningful work is fundamental to citizenship in Australia. Currently there are obstacles from the early years, in schools and in employment opportunities. A scheme needs to recognise that people with disabilities have the same aspirations as their peers.

Participation in community events also needs to be supported. Captioning or audio description in cinemas and accessible recreation facilities are two examples. The more accessible mainstream community facilities and services are, the less likely people with disabilities will need disability-specific supports. An inclusive community will increase learning opportunities and experiences for young children and their wellbeing when they reach adulthood.

A National Disability Scheme should have a legislative basis and a discrete administration structure to oversee the initial assessment, review, payments and so forth. The governance of the scheme should allow for participation by and advice from people with disabilities and their families. A scheme should be funded by a levy similar to Medicare levy. This would ensure that the cost is spread across society, and would provide ongoing adequate funding to meet the needs of all Australians with disability.