



The Royal Australasian
College of Physicians

**The Royal Australasian College of Physicians
Paediatric & Child Health Division**

**Position Statement
Early Intervention for Children with Developmental
Disabilities**

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Early Intervention for Children with Developmental Disabilities

Executive Summary

Children with developmental disabilities can lead a rich and rewarding life, yet as a group, are among the more vulnerable within our community.

Early intervention for children with developmental disabilities involves timely provision of an optimal nurturing and learning environment that aims to maximise developmental and health outcomes and reduce the degree of functional limitations. It is a system of coordinated services that promotes the child's growth and development and supports families during the critical early years. Early intervention can provide primary, secondary and tertiary prevention. Promotion of long term health and wellbeing through early detection of determinants of adverse outcomes should be a feature of early intervention programs.¹ Early intervention is of clear benefit to children with developmental disabilities. This position statement focuses predominantly on intervention for children with disabilities during the early childhood years, often referred to as early intervention by families and service providers.

Early intervention ideally follows early identification of developmental problems. When developmental problems are identified, a comprehensive assessment and diagnosis must be carried out. It must examine the functional abilities, developmental diagnoses, health conditions and other factors likely to influence future outcomes and wellbeing. Identifying these factors enables parents and professionals to better match the intervention and support to the child and family's needs.

There is evidence that providing support and services for infants and young children with early developmental impairments and their families can alter the child's longer term developmental trajectory, and reduce the risk of secondary health and psychosocial complications. Early intervention programs are best delivered in a coordinated, planned, family centred manner that reflects a lifecourse approach to health and wellbeing outcomes. Supporting the family is a crucial component of early intervention programs, as the family has a key role in fostering their child's developmental potential and may experience additional stresses as they meet the special needs of their child. Even when the child might continue to experience significant limitations in their day to day skills, early intervention can improve function and increase the ability of the family, services and the community to support and include the child.

Recommendations

Overarching Principles

1. Early intervention services for children with a disability should be aligned with the United Nations Convention on the Rights of the Child and the Convention on the Rights of People with Disabilities.
2. Inclusion of children with disabilities in all community activities is a means of creating societies in which all people with disabilities are accepted and valued.
3. Early intervention is more effective if delivered across all environments, including home, child care, other educational settings and all places that children access.
4. The families of children with disabilities should receive appropriate support to maintain their health and wellbeing.
5. A person-centred approach, and family-centred practice, in which the needs of the child and their family are prioritised should characterise the service system.
6. It is important that children with disabilities experience equity of access to intervention and other services, and are not discriminated against through requirements of programs for the child to have a medical diagnosis.

Prevention of avoidable health problems

1. Public health initiatives that reduce the occurrence of preventable conditions such as acquired brain damage (e.g. near drowning, shaken baby syndrome), exposure to toxins such as lead or alcohol, and vaccine-preventable diseases, should continue to be promoted.
2. It is important to increase awareness of and implementation of strategies to reduce those conditions that occur more commonly in children with disabilities, e.g. mental health problems.

Early intervention; the first stage of a comprehensive lifecourse model of care

1. Specialist early intervention services must be evidence based, or in the absence of evidence, based on expert consensus.
2. All children with disabilities and developmental delays should have access to high quality early childhood education and care services that support and enhance their functional participation.
3. It is important to implement strategies that enable early detection of children with disabilities so that timely intervention can be offered.
4. The goals of intervention should be comprehensive, and in addition to the improvement of functional skills and abilities, encompass those factors that are associated with longer term wellbeing of the child and family. An ecological approach to therapy, with an emphasis on family as a major influence on their child's early development, supported and educated by early intervention services, should be evident.
5. Early intervention services should map clearly onto a lifecourse framework that recognises the long term nature of the disabilities and the impact of critical periods of transition for the child and family (chronic disease framework).
6. Early intervention services are best delivered within a reasonable proximity to where the child lives.
7. Distinctions between health conditions and disabilities or impairments should be maintained. A particular health condition can be associated with varying degrees of impairment.
8. Parents and other carers better advocate for their child if they understand their child's diagnoses, abilities, personal strengths and ongoing needs for support and services as they will remain the most significant advocate for their child.
9. Multidisciplinary models of care should be established at the time of diagnosis. These should be characterised by effective and sustained collaboration across sectors, health, disability, education and family and community services, and professionals.

10. For those children who are predicted to continue to have significant activity limitations, services should continue to assist them to access the community and educational and other services as a valued member of that community.

Access to and planning of early intervention services

1. Eligibility for specialist early intervention services is most appropriately determined by comprehensive assessment of the child's functional abilities. The identification of an underlying health condition may assist with treatment planning, but rarely determines the child's responses to education, therapy or support to families.
2. Service planning and delivery should include consideration of parent/carer priorities as well as other factors that influence outcomes and responses to intervention.
3. Individualised plans in which clearly articulated and relevant developmental or learning goals for the child should inform delivery of multidisciplinary early intervention services.
4. In Australia, major service reform involving simplification and increased responsiveness of models of care and funding, removal of barriers to health and other systems of care, increased collaboration across sectors, better referral pathways, and improved transition across lifestages are required to deliver more effective services.
5. A closer collaboration between diagnosticians and early childhood intervention (ECI) services could determine better sharing of information about diagnosis, prognosis, treatment and interventions with families, supporting them to adjust to the special needs of their child.
6. Increase funding for research of intervention for children with disabilities with an emphasis on translating that research into clinical practice.
7. Paediatricians should contribute their professional and clinical expertise to the development of policy and service models of early intervention for children with disabilities.

Early intervention for children with developmental disabilities

Introduction

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.² There is evidence that effective early intervention can positively alter the child's longer term trajectory³, achieve significant savings⁴, and potentially reduce the risk of secondary health and psychosocial complications

The International Classification of Functioning, Disability and Health (ICF) defines disability as an umbrella term for impairments, activity limitations and participation restrictions. Disability is the interaction between individuals with a health condition (e.g. cerebral palsy, Down syndrome and depression) and personal and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limited social supports).⁵ A given health condition might be associated with a range of disability levels, or even none.

Children with developmental disabilities can lead a rich and rewarding life, yet as a group are among the more vulnerable within our community. Typically, they will be involved with numerous professionals and organisations from an early age, and may not fully participate alongside their peers in community and educational activities. Children with disabilities are likely to experience higher rates of mental and physical health problems, and increased requirements for general health services.

Early intervention programs are best delivered in a coordinated, planned, family centred manner, which reflects a lifecourse approach to health and wellbeing outcomes. Even when the child continues to experience significant limitations in their day to day skills, early intervention has the capacity to improve function and increase the ability of the family, services and the community to support the child. Commitment by professionals through these early years to the child and family is important as the parents come to understand the longer term prognosis and adjust to the special needs of their child.

Understanding Developmental Disability

Developmental disability is a permanent cognitive and/or physical impairment that usually occurs in the early years of life but can occur any time before the age of 18 years.

Disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.⁶ The World Report on Disability⁷ stresses that disability is the umbrella term for impairments, activity limitations and participation restrictions. It refers to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).⁷ "Health conditions" are diseases, injuries, and disorders, while "impairments" are specific decrements in body functions and structures, often identified as symptoms or signs of health conditions. Health conditions on their own are not the same as disability. Children with disabilities may not think of themselves as having a disability. "Therefore working with children with disabilities requires carefully tailored approaches. Labelling a child solely in terms of their health condition should be avoided. They are children first and aspire to participate in normal family and peer-group activities."⁸

Terminology: Developmental Disability or Developmental Delay?

Global Developmental Delay (GDD) can be defined as *the situation where there is either a delay in acquisition of developmental tasks or milestones, or (less commonly) a disorder of development in which milestones are achieved but qualitatively different (such as with disordered word combinations, or some personal-social milestones)*.⁹ The current use of the term has been shaped by the Practice Parameter of the American Academy of Neurology, which defines GDD as *a subset of children with developmental disabilities who have a significant persistent (at least for 6 months) delay (performance 2 standard deviations or more below the mean on age-appropriate, standardised norm-referenced testing) in 2 or more developmental domains*. It can be a misleading and imprecise diagnostic term for children from zero to five years who present with multiple developmental problems.

There are a number of problems with this terminology. It is not necessarily associated with prognosis in particular cognitive impairment.¹⁰ The children to whom the term is applied are, for the most part,

not affected in all domains and it offers no descriptors as to the domains of delay. Thus some experts believe that the term Global Developmental Delay is inherently limited.¹¹ Many of the children are not simply delayed, which would imply catch-up; rather, they are impaired. Further, the diagnosis implies to parents, caregivers, and therapists that the condition is temporary and prognosis favourable. If the child fails to catch up, disappointment, anger, and frustration may ensue. Among clinicians, there is no clear consensus about whether cognitive skills must be affected for the term to be applied, and this is evident in the definitions noted above.

The term “developmental disability” may be a more useful term. The US Centers for Disease Control and Prevention (CDC) define it as *a permanent cognitive and/or physical impairment that usually occurs in the early years of life but can occur anytime before the age of 18 years* thus time being the crucial component. However, its usage in the early years of life may be limited as it may be difficult to predict the longer term developmental trajectory.

The term “developmental trajectory” describes the course of development over time and has been used to describe behaviour in psychosocial research.¹² It does need to be emphasised that environmental factors remain important for all children’s progress.

Developmental disabilities are common

Developmental concerns are very common during early childhood years,^{3, 13} however a smaller proportion of children are likely to experience a significant ongoing developmental disability. In Australia, approximately 300,000 children in Australia have a disability,¹⁴ or about 7.6% of the child population aged zero to fourteen. Globally, about 15 per cent of the world’s population lives with some form of disability, of whom two to four per cent experience significant difficulties in functioning.⁷

The human rights implications for early intervention services

There are increasing calls for adopting a human rights based approach to planning and delivering health services for people with developmental disabilities in Australia.¹⁵ Tangible evidence of such an approach includes: improved policy with measurable outcomes, improved service access via clear referral pathways and the sharing of resources across disability and (mental) health services, and improved service delivery through training and education initiatives for both the mental health and disability workforce. This approach emphasises that even in the absence of likely significant cognitive gains to be made from early intervention, the child with disabilities should nonetheless receive support to continue to enable them to participate in their family and community.

Both the UN Convention on the Rights of the Child and UN Convention on the Rights of Persons with Disabilities have relevance for provision of early intervention for children with developmental disabilities.

UN Convention on the Rights of the Child –Article 23 recognises that (summarised):¹⁶

1. A mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community.
2. The right of the disabled child to special care ...and assistance for which application is made and which is appropriate to the child’s condition and to the circumstances of the parents or others caring for the child.
3. Assistance...shall be provided free of charge...and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child’s achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.

UN Convention on the Rights of Persons with Disabilities Article 26, Habilitation and Rehabilitation, calls for:

... appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.⁶

Implementing a planned and connected system of services

A comprehensive approach is required for the provision of care and support for children with developmental disabilities encompassing diagnostic, health, disability, education and intervention services. Service models should recognise the special needs of children with disabilities and their families during the first years of life,^{*} and also provide support within a framework that is based on principles that will remain relevant throughout the lifecourse. The impact of developmental impairments on daily functioning may become increasingly apparent during the early years, yet clarity regarding an overall diagnosis may take longer to establish. This phenomenon can frustrate families and professionals who work within and with systems based on eligibility criteria centred around a diagnosis.

Extensive evidence exists that our systems of care for young children remain excessively complex and fragmented, characteristics that risk limiting effectiveness of interventions.¹⁷ Many attempts have been made to coordinate systems more effectively, both locally and internationally, yet these too may add to the complexity with different types of intervention, methods of determining eligibility and principles of care.

Children with disabilities may be exposed to additional risks that can further compound adverse health and wellbeing outcomes.¹⁸ There is growing evidence that a large proportion of this inequity is due to factors other than the primary/biological cause of their disability.

The impact of caring for a child with developmental disability may be cumulative throughout the lifecourse. Persistent, constant demands for care and support can be exhausting for carers, who are sometimes referred to as “perpetual parents” (Grant et al., 2003)¹⁹. The Australian National Carer Strategy²⁰ provides a framework for services to recognise and respond to the important roles carers have in the health and wellbeing of people with disabilities.

Provision of optimal environments for developmental progress, health and wellbeing

Universal programs at a primary care level should be aimed at identification of children at developmental risk. When a child is identified at developmental risk then early intervention should be tailored to individual needs.

It is clear that a number of environmental factors can influence child development. Many are clearly known to affect brain development both in utero and ex utero for example drugs, alcohol and lead poisoning. However it is also known that other environmental factors such as poverty, nutrition, trauma and parental mental health have significant associations with a child’s development and longer term outcomes.²¹ New evidence suggests that extreme environmental influences can modify DNA methylation and hence genetic transcription of a number of factors critical to brain development and these effects may be permanent. The critical periods in brain development may indeed offer both a vulnerability to both adverse environments and potential positive effects from early intervention. This position statement recognises the importance of public health measures and the contribution of paediatricians to these important initiatives in addressing the prevention, early recognition and interventions for children with developmental disabilities.

A comprehensive prevention framework for developmental disabilities may be understood in terms of the public health approach to reduction in morbidity. This distinguishes between primary prevention (population-wide approaches to remove or reduce the cause of a health problem before it arises), secondary prevention (actions to detect and minimise a health problem at an early stage) and tertiary prevention (actions to reduce the impact of an already established disease by restoring function and reducing disease-related complications).

* “Early childhood” is understood as per the World Health Organisation definition as the period from prenatal development up to the age of eight years, cf. *Early child development: a powerful equalizer*, available at http://www.who.int/maternal_child_adolescent/documents/ecd_final_m30/en/, accessed 17/05/2013.

Primary prevention initiatives include efforts to prevent those developmental disabilities due to known toxins or injury, such as fetal alcohol syndrome or lead toxicity. Although more research is needed to improve interventions, current knowledge is adequate to warrant the expansion of existing prevention programs. Past initiatives, such as prevention of Rhesus isoimmunisation associated haemolytic disease of the newborn and subsequent kernicterus causing deafness and cerebral palsy have had major benefits for children. The message of “no alcohol in pregnancy is safe” must be given unambiguously

Secondary prevention is important for children with developmental disabilities in order to improve health and reduce the well established risk of adverse health problems in later childhood and adult life. There is limited data on the trajectory of secondary health complications such as obesity, but some evidence does demonstrate that risk rises as early as 6-8 years of age.²² Early intervention services should address the determinants of these outcomes, for example, social adversity, behaviour management strategies, active and healthy lifestyles, as intervening early has the best chance of improving outcomes.

Tertiary prevention targets existing conditions by intervening early with the aim of improving outcomes. Children with challenging behaviour or mental health conditions benefit from early intervention to reduce the longer term risks of placement or family breakdown, exclusion from services such as school, and additional adverse health risks.

Assessment and Diagnosis

Assessment and diagnosis of the child with developmental disability is a critical and often stressful period for parents.^{23, 24, 25, 26} Services provided at this time should not only enable expert clinicians to deliver best practice and accurate diagnosis, but also the level of support and counselling that will assist parents, before during and after diagnostic assessment. There is good evidence that the parents' initial experiences with health professionals at this critical time can have a major and lasting influence on their ability to cope with their child's condition.^{27 28 29} Clinicians should be open and honest with families about the child's condition, sensitive to the families' circumstances and needs and portray a positive view of the child.³⁰

Diagnostic assessment should be based on a comprehensive ecological framework, and anchored in a strengths and resilience focused approach to understanding the child.³¹ Close and effective collaboration amongst professionals is important to ensure consistency across professional opinion and recommendations. Interdisciplinary approaches (allied health and medical, early education and others working to support the child and family in both specialist and universal services) are key to an accurate understanding of the child in their family context. More accurate prediction of responses to treatment may be achieved with such an assessment.

A comprehensive assessment should elucidate both *diagnostic* and *functional* elements. Diagnosis involves the identification and interpretation of symptoms and signs (neurological, behavioural, and physical) in order to describe a health condition and determine degree of functional abilities, define a cause where possible, estimate prognosis, and guide appropriate investigation and management. Diagnosis might involve the application of a categorical label, which can define a condition by behavioural phenotype (for example, autism), physical syndrome (such as cerebral palsy), or biological aetiology (for example, Fragile X syndrome). Diagnostic labels, however, may reveal little about how a child is functioning,⁴⁰ and thus do not necessarily predict service needs.^{32 33} An assessment of function is associated with diagnosis and is required to plan and implement interventions.⁴⁰ It is improvements in function, rather than change in diagnostic status, which are useful in the evaluation of outcomes.⁴⁰ Labels may also say little about environmental influences on a child's function, the salience of which is incorporated into contemporary models of disability.^{31 34 40 41}

Early intervention

Early intervention for children with developmental disabilities refers to timely provision of an optimal nurturing and learning environment that will maximise developmental outcomes and prevent activity based, functional and participation limitations. It is a system of coordinated services that promotes the child's growth and development and supports families during the critical early years.

There is evidence that early identification and intervention improves outcomes both for the child and for the family. In general intervention is more likely to be successful when it focuses as much on supporting and training parents as it does on directly working with the child.

The concepts of “vulnerable” or “critical” periods in development are also mentioned as an opportunistic time for maximum influence on outcome. “A **critical period**” is a phase in the life span during which a child has heightened sensitivity to exogenous stimuli that are required for the development of a particular skill. Pruning or selection of active neural circuits takes place throughout life, but is far more common in early childhood. For many this may be in the first 2 years of life when brain connections are being made and the brain is at a period of maximum growth and plasticity. Other important periods of brain growth and development occur during the lifespan.

A meta-analysis in 1986 examined the effects of early intervention services on a broad range of children with disabilities younger than 3 years of age, and their families.³⁵ Results indicated that early intervention is effective in promoting developmental progress in infants and toddlers with biologically based disabilities. Programs oriented towards less severely affected children, which enrolled children before 6 months of age and encouraged high levels of parent involvement, achieved the best outcomes.³

Expert review³⁶ of early intervention for children with specific types of disabilities, such as autism, is often informative for the broader population of children with disabilities. Even if it is not possible to recommend a specific programme that is suitable for all children with disabilities, it is possible to draw conclusions about characteristics of more successful programs. These include provision of specific curricula, highly supportive teaching environments, involvement and engagement with families and strategies to support generalisation of acquired skills.³⁶ Goal directed therapy should be recognised as being able to be tailored for individual needs. Therapy should have goals and regular reviews by experienced clinicians as to outcomes and attainment of goals.

A review of the effectiveness of early intervention³⁷, identified that there was limited research specifically related to intervention for children with disabilities. Further high quality research exploring the benefits of early intervention is urgently required in order to inform more effectively how early intervention can be delivered to achieve best outcomes for children and families.

Research evidence on its own is not sufficient to determine access to and the type of early intervention required. The UNCRPD and UNCRC clearly articulate the human rights imperative to provide support to enable the child to access educational and other services. Specialist therapy and educational intervention may be required during preschool years in order for the child to be in the mainstream or supported education system.

Eligibility criteria

A threshold for early intervention programs should be identified as those children at significant risk of adverse developmental outcomes for whatever reason (biological, environmental or a combination of both). This might include developmental delay/developmental disability, atypical development, known medical situations of high risk for poor developmental outcomes or significant exposure to environmental factors. Each child at risk should have access to services to maximise developmental outcomes.

Determining eligibility for early intervention services on the basis of diagnosis, or health condition, may result in unintended consequences. The impact of developmental impairments on daily functioning may become increasingly apparent during the early years, yet clarity regarding an overall diagnosis (with distinctive symptom pattern and predictable natural history) may take longer to establish.

Early intervention service models with diagnosis-based eligibility criteria can encourage the premature, clinically inappropriate application of diagnoses with long term implications in situations where uncertainty exists. The exercising of more prudent clinical practice, in which appropriate time is allowed for the clinical picture to become clear, can paradoxically result in frustration for families and professionals, as children with significant functional impairment, yet without one of the “eligible” diagnoses, are excluded from interventions that may also benefit them.³⁸

It is essential that children with functional disabilities are not discriminated against through requirements for specific medical diagnoses to gain access to intervention and other services.

It is recommended that eligibility for early intervention services be determined primarily by profiling and measuring a child's functional impairment. The presence of a categorical diagnosis may help, in a broad sense, with treatment planning, but should not by itself serve a gate-keeping role. Effective early intervention can begin before formal diagnosis, purely on the basis of the child's functional abilities and support needs.

A framework for organising data on a child's functioning, and tools for measurement of function (impairments and strengths), are necessary for eligibility determinations.

A prominent example of a standardised framework for the description and classification of the functioning of children exists in the form of the International Classification of Functioning, Disability and Health – Children & Youth Version.³⁹ The ICF-CY, and its adult equivalent (ICF) has been applied in different sectors (for example, disability and education) and in a range of locations worldwide. It provides a “common language” to enable cross-disciplinary communication.^{40, 41} A wide variety of standardised tools exist for the evaluation of functional impairments and strengths, which have the capacity to map on to the ICF-CY framework. Measures of function can also be used to monitor progress, with intervention stepped up or down as necessary (for example, the tiered approach of Response to Intervention models).⁴²

Paediatricians play an important role in supporting children with developmental disability

Paediatricians are in a position to advocate for all children irrespective of their potential contribution to society or the financial return on investment made by government.³⁷ Research continues to demonstrate the involvement of paediatricians in diagnosis and management of children with learning and behavioural conditions, with these representing nearly 30% of clinical caseloads.⁴³ Paediatricians are involved in the identification, diagnosis, and management of children and young people with developmental disabilities. They also take a holistic view of contributing medical and psychosocial influences and support understanding of the contribution these factors make to a child's functioning.

Paediatricians are integral to the provision of health and diagnostic services for children with developmental disabilities. Specialist children's health services, including consultant paediatricians and multidisciplinary diagnostic and assessment teams, may be accessed by some children with developmental disabilities and complex health needs.⁴⁴ Paediatricians have long provided leadership in the early childhood and disability sectors and have strongly advocated for improved recognition of the importance of the early childhood years and models of care for children with developmental disabilities. Paediatricians in Australia and New Zealand such have held senior government roles, led national research alliances, and been appointed national children's commissioner, with many more toiling away within their local networks.

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