

**Community Development and Justice Standing
Committee**

**Inquiry into the Adequacy of Services
to
Meet the Developmental Needs of
Western Australia's Children**

**Disability Services Commission
146-160 Colin Street West Perth 6005**

Introduction to the Commission

The Disability Services Commission, established in December 1993 under the Disability Services Act 1993 (WA), is the State Government agency responsible for advancing opportunities, community participation and quality of life for people with disabilities. The Commission provides a range of direct services and supports and also funds non-government agencies to provide services to people with disabilities, their families and carers.

In accordance with the Disability Services Act, 'disability' means:

- attributable to an intellectual, psychiatric, cognitive, neurological, sensory, or physical impairment or a combination of those impairments;
- permanent or likely to be permanent;
- may or may not be of a chronic or episodic nature; and results in
- a substantially reduced capacity of the person for communication, social interaction, learning or mobility; and
- a need for continuing support services.

Not all services for people with disability are within the jurisdiction of the Disability Services Commission. People with disabilities access government and community services along with other Western Australians. In supporting young children and their families the Commission particularly recognises the roles of the Departments of Health, Education and Training, Child Protection, Communities and Ministry of Housing.

The Commission is funded by the Western Australian Government and, through the National Disability Agreement, the Commonwealth Government.

Over 1,000 young children 0 to 4 years have been accepted as eligible for services provided and funded by the Commission. They have a range of conditions.

- Intellectual disability such as Down Syndrome, Fragile X, tuberous sclerosis, other genetic and neurological syndromes
- Autism Spectrum Disorder
- Global Developmental Delay (where no specific diagnosis has been made);
- Physical disability such as Cerebral Palsy, Muscular Dystrophy, Spina Bifida, Paraplegia, Quadriplegia and Hemiplegia
- Vision impairment
- Hearing impairment
- Acquired brain injury
- DeafBlind

Children may have multiple disabilities and additional disorders such as speech and language and specific learning/attention deficit co-morbid with their primary disability.

The Commission supports eligible young children and their families by funding and directly providing a range of programs. Early childhood intervention in the metropolitan area is provided by disability specialist government and non-government services and in regional areas provided by the Department of Health (WA Country Health Service) with consultative support from the Commission and other non-government organisations with a state wide focus. Linkages with Aboriginal Health agencies in regional areas is an important strategy for supporting indigenous children with disabilities and their families and carers.

In conjunction with early childhood intervention, the Commission provides or funds:

- Local Area Coordination to assist children and families plan and access community support;
- respite, in and out of home;
- specialised equipment; and
- advocacy, parent to parent and individual family support.

The Commission supports up to date evidenced based approaches to early childhood intervention. On this basis:

- services are family centred, based on a partnership between parents and professionals, with direct intervention having a family and carer, as well as child, focus.
- service delivery recognises family functioning within a wider social context and the importance of a family and community network of social support;
- interdisciplinary and trans-disciplinary teamwork provides an integrated and coherent program with a key worker for easier contact;
- inclusion in mainstream settings is viewed both as a right and as a major evidenced based intervention strategy. Inclusion necessitates additional support for universal service; and
- services recognise that comprehensive, cohesive systems and linkages across both public and private sectors deliver better outcomes for children and their families.

Terms of Reference

a) Whether existing government programs are adequately addressing the social and cognitive developmental needs of children, with particular reference to prenatal to 3 years

The Australian Bureau of Statistics (ABS) estimates that the prevalence of severe and profound core activity limitation is 4.1% of children 0 to 4 years, ie approximately 5000 children in Western Australia.

Disability projections for the period 2008 to 2013 indicate a 3.9% growth in the preschool age group, less than 1% a year. This number is derived from the population projection and the prevalence of disability in this age group.

Approximately 1,000 children 0 to 4 years are in receipt of funded early childhood intervention. Referral rates increase markedly in the year children are enrolled in kindergarten and jump again at enrolment in year one.

1. The Disability Services Commission has responded to the increasing rate of referrals for disability early childhood intervention.
2. There has been an 85% growth in funding for Disability Professional Services over the last five years. This is real growth to respond to unmet need and is in excess of growth in the WA population and prevalence of disability. The bulk of new funds has been directed to early childhood intervention and school age services.
3. The Commission's budget for Early Childhood Intervention is now \$6.9m.
4. In addition, the State Government has made a commitment to further increase the number of early intervention places.

Key Issues

It is not known how many of the 4000 children estimated by ABS as at risk but who are not known to the Commission in their preschool years:

- have been in receipt of appropriate services from other government or non- government agencies;
- are on the pathway of referral and assessment;
- have families who have been advised to 'wait and see';
- have families and carers unaware that a child's experiences in the early years have a major impact on their future development; or

- have not been involved with any universal program and their developmental needs remain unrecognised.

The pathway, from first concern to developmental screening, referral for diagnostic assessment and further referral for determination of eligibility for a disability specialist service, involves a number of agencies and professionals and can be quite complex for families and professional alike. At each stage there can be bottlenecks with the risk that the process can take so long some children miss out altogether on intervention in the important early years.

Essential features of effective intervention programs include individualisation of service delivery, program quality based on research evidence, provider knowledge and skills, a positive relationship with the family and carers and timing, intensity and duration of the intervention.

The Commission requires preferred providers of early childhood intervention to comply with Disability Services Standards and specific principles and guidelines consistent with recommended practice.

While the Commission has been able to respond to the growth in referrals and keep waiting lists for service access to a minimum, there are shortfalls in the level of service intensity. The Commission is well aware of this shortfall and in 2009 will increase the funding per place to enable services to boost the amount of support they can provide, particularly for children with high support needs.

Children who are most likely to miss out on early childhood intervention are children from families with multiple and complex needs, who are marginalised, living in outer metropolitan and regional areas and children whose development is delayed or disordered without a specific diagnosis. Families may be known to many agencies without any having the capacity to respond to their needs comprehensively.

Services in rural and remote areas are variable and dependent on the individual attitude, knowledge and skills of the current allied health workforce. In country areas there can be a high staff turnover with gaps in service availability.

Recommendation

- A better understanding of the experiences of families and children on their journey to specialist services, particularly those who are late to receive assistance.
- The capacity of the Telethon Institute for Child Health Research data linkage to contribute to increased knowledge of identification and referral patterns to be considered.
- Review of referral processes across agencies to eliminate bottlenecks and delays in access to appropriate programs.
- A more targeted approach to children and families from backgrounds where different approach is needed.

- An integrated approach to provision of universal, targeted and specialist services to increase the capacity of universal services to respond quickly and appropriately to emerging developmental concerns.

b) How to appropriately identify developmentally vulnerable children

It is a well established principle that early identification and prompt action are critical to positive outcomes for children with disability and developmental delay.

Access to specialist input for children with disability is dependent on children being identified as at risk prior to referral for assessment, diagnosis and intervention. The needs of children with delays that are not readily apparent may be missed.

As well as targeted services for children from backgrounds that have traditionally not participated in early years programs, children from families stressed by living arrangements such as 'fly in fly out' employment may also need a carefully crafted response to meet new challenges to family life.

Recommendation

Early identification of children with developmental concerns requires a multi-strategic approach and use of standardised tools.

- Increase the knowledge of those closest to the child, parents, carers and professionals about development, milestones and typical behaviour.
- Specific approaches to engage families, such as non English speaking families and aboriginal families, that are less likely to be involved with mainstream services. Joint services with and increasing workforce capacity of organisations that families know and trust would streamline access to the intervention children need.
- Multiple opportunities for developmental screening at a number of key stages: child health nurse checks, immunisation, GP visits, enrolment in childcare and kindergarten.
- Visits to and written information at community centres and playgroups and crèches.
- Advertise reputable sources of information and advice such as web sites (Raising Children Well) and parent hot lines and place information at key family locations.

c) Which government agency or agencies should have coordinating and resourcing responsibility for the identification and delivery of assistance to 0–3 year old children

The life of a young child is intrinsically bound to the life of their family and all service strategies for the age group (0 to 3) need to be cognisant of this as a primary guiding principle.

Children with developmental delays and their families may be known to, and receive services from, a myriad of government (State, Commonwealth and local) and non-government agencies, all with their own mandate to support family wellbeing and child development.

Children's services address a wide range of domains, and approaches used are the outcome of different sets of knowledge held by different departments about health, development, care early learning, protection, community and social development and cultural support. The foci of departmental, non-government agencies and peak bodies often overlaps. This can provide a common goal but also misunderstanding and duplication and conflicting advice for families.

Academic sectors also have a major role in contributing to the wellbeing of children and families through research evidence of program effectiveness and work force development.

No one agency has the complete picture. There is an almost unanimous view that current services for young children are fragmented and confusing for parents and service providers alike with scarce resources either repeating procedures such as assessments and case management plans or allow some children to fall through gaps in service alignment.

Recommendation

The development of a integrated approach to government planning for children's early years with the goal of a common framework within which the range of children and family needs are identified, broad service strategies set and departmental roles, service, responsibilities and linkages delineated.

d) What is the best model to ensure interagency and intergovernmental integration of developmental programs delivered to 0–3 year old children

Young children's needs can not be separated from the needs of their families and communities. All children, but particularly children with special needs, do best when there is a network of family, neighbourhood and community supportive connections and an easily accessible service system covering health, development, care, protection, early learning, social opportunities.

The current system of responsibilities divided between several departments from State, Commonwealth and local government has led to duplication, service gaps and inequities and confusion and complexity for families.

To provide effective services for vulnerable children and families, both those involved with numerous agencies and families who traditionally have had limited contact with programs, a streamlined support system is essential.

Inclusion for children with disabilities in community life and mainstream services has long been the vision of the Commission and collaborative practice is a key strategy. To ensure that services for children with disabilities are not viewed as the sole responsibility of the disability sector and separate to other early childhood programs, careful consultation with families and local services, planning, additional resourcing and community and service support are required.

Success has been variable but is more likely when there are common goals, agreed strategies, understanding of the shared and different roles and responsibilities of the agencies involved and common performance indicators. Co-location is useful but without a collaborative work framework is not sufficient.

Sustaining a more integrated approach is dependent on maintaining and funding collaborative mechanisms endorsed at all levels from director, senior management, direct services and community groups, and outcomes are reported to a single point of accountability.

Recommendation

The Commission believes that children with disabilities would be a key group for any overall state plan for young children. There would be considerable benefits for their families in accessing a more coherent system with clear linkages between various specialist services and local universal programs.

Increasing funding to separate specialist programs to enable them to meet all the needs of their target group is prohibitive. Better value will be achieved by ensuring needs can be met within a seamless system without duplication,

multiple assessment and conflicting approaches. Most children are participating in local universal or community programs. Specialist input to assist programs meet the needs of developmentally vulnerable children and provide additional intervention if required could result in more opportunities for children to be engaged earlier in activities and interactions which promote their development.

The Commission would be pleased to support and contribute to planning for a more coordinated system of early childhood services in WA.

e) How to best prioritise the resources available for meeting the needs identified

Views as to the priority for scarce resources will vary from the program which will result in the biggest immediate gains to the program providing services to those who are most disadvantaged.

The COAG agenda provides a ready made set of outcomes and objectives. A WA consultation process could determine to what extent these objectives are being met in WA and the areas we are falling behind Australia/international benchmarks.

The Australian Early Development Index provides an evidence base for determining which developmental domains are a priority for intervention and which demographic groups are most disadvantaged.

Recommendation

In Western Australia there have been a number of pilot programs which have demonstrated positive outcomes. Such programs have been both broad approaches such as the Early Years Strategy or highly structured such as Stepping Stones, behavioural support for parents of children with disability. Additional funding to extend successful proven programs to other locations and other target groups would be an immediate step, while a more comprehensive approach to setting across departmental and sector priorities is developed.

f) What is the most appropriate measure of program outcomes

The Australian Early Development Index, first trialled in Western Australia, has been adopted and funded by the Commonwealth Government as a national population measure of children's development. It is in current use and has demonstrated that communities have responded to its findings about the developmental needs of children in their local areas.

Use of the index can assist targeting for a range of programs for parents and communities about their role in children's health, early learning, social development and community participation. It can assist schools to prioritise remedial activities in areas of developmental vulnerability.

The Index collects information about children with special needs and could be used to identify where resources should be directed and what domains are a high priority for intervention programs.

Recommendation

Consideration of the Australian Early Development Index as an ongoing measure of children's early development and early childhood programs outcomes.