

Submission  
No 84

**INQUIRY INTO SERVICES PROVIDED OR FUNDED BY  
THE DEPARTMENT OF AGEING, DISABILITY AND  
HOME CARE**

**Organisation:** Early Childhood Intervention Australia (NSW Chapter) Inc.  
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**Submission to the NSW Parliamentary  
Inquiry into services provided or funded by the  
Department of Ageing, Disability and Home Care**



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Early Childhood Intervention Australia (NSW Chapter) Inc. [ECIA NSW] is the peak state-wide organisation promoting the interests of young children with developmental delays and disabilities and their families. The majority of our members are early childhood intervention (ECI) professionals working in ADHC-funded agencies. They are based in urban, rural and regional centres throughout the state.

A central focus of ECIA NSW is fostering and advocating for the provision of quality, comprehensive ECI services, accessible on an equitable basis, that can offer responsive support within their local community to all young children with disabilities and developmental delays and their families.

The critical importance of these early years is well-recognised. It is extremely cost-efficient, as well as a clear, fundamental human right, that governments promote the optimal development of all young children through well-funded initiatives that effectively support the foundations of learning, family resilience and social inclusion.

Our submission will mostly address the services provided by ADHC-funded agencies, given both the background of the majority of our members and the relatively small proportion of ECI services that are offered directly by ADHC. Each issue within the Terms of Reference is discussed and our recommendations presented at the end of each section.

## **(a) The historical and current level of funding and extent of unmet need**

### ***Historical***

Prior to the Government's *Stronger Together* initiative, the ECI service sector had received negligible funding increases. Those that occurred were often ad hoc, one-off grants when funds remained at the end of a financial year. These did little to reduce the availability of ECI services to families on the long waiting lists across the state, or to allow provision of a more effective level of intervention to those accessing services.

### ***Currently***

It has been a welcome development that in the first five years of *Stronger Together*, there have been increases to the services provided to some children and their families in NSW, as well as improvements to resources and trialling of new models of service delivery. *Stronger Together* has delivered targeted additional funding to parts of the ECI sector, which has increased service availability in some geographical areas. New funding was distributed through the following initiatives: *Extending Early Childhood Intervention Initiative* (which included Enhancing Services), *EarlyStart* (for education and therapy programmes supporting inclusion and transition for children and families within their local communities), *Therapy Transition Program* (focussed on supporting access to mainstream school) and *EarlyStart Diagnosis Support* (early information and support for families).

The new funding has enabled recipient organisations to increase their service capacity significantly. There has not, however, been an equitable distribution of this funding and there remain very differential levels of access to services by families of young children with disabilities and delays across the state. A small number of end-of-financial-year allocations have been made recently to a few organisations, although the basis and time-frame for these was not totally clear. In addition, the organisations funded under *Stronger Together* have not yet been informed of what will happen beyond the current contracted period (which ends between December 2011 and June 2012), so their capacity to sustain the expanded programmes longer-term is very uncertain.

### ***Unmet need***

- Long waiting lists for services still remain a constant concern for families and service providers. A common response to long waiting lists is for organisations to consider stretching available resources even more thinly, in an attempt to accommodate family needs. Not only does this have an absolute limit, but there are evident undesirable outcomes for all children and families accessing a much lower level of intervention and support than is required.
- Determining the full extent of state-wide waiting lists in the absence of a formal data collection system remains difficult. In recognition of this issue, ADHC has recently funded a Therapy Data collection project which has been compiling information from funded organisations (all age groups) regarding those waiting for therapy. While a positive initiative, limitations of this data collection process have a significant impact on ECI: the waiting list data relates only to therapists (speech pathologists, occupational therapists and physiotherapists) and currently has no scope to consider the role of early childhood special education teachers, who offer a critical component within best practice, family-centred ECI. In many parts of the state, such teachers are the sole provider of ECI services, in the absence of any therapy input; and in the overwhelming majority of ADHC-funded ECI programmes, they are the primary interventionists.
- Other more specific elements of unmet need are reflected in the under-representation of families from culturally and linguistically diverse (CALD) and Aboriginal backgrounds in most services. While many staff in service agencies have undergone training that has assisted them in better understanding the particular needs of these groups, and as a result, strive to provide an inclusive and welcoming approach to all families, a number of barriers remain. Issues such as the variable availability of interpreters can result in significant difficulties in ensuring culturally appropriate information and access to families from CALD backgrounds. And in relation to Aboriginal families, while individual services

have implemented some encouraging collaborative initiatives with local Aboriginal services, such as health and child care centres, additional strategies are required. One attempt at this was the specification for those agencies in receipt of the general *EarlyStart* funding that a targetted number of Aboriginal children and their families be supported within a particular area (based on ABS population figures). There were also 8 Aboriginal-specific Early Diagnosis support worker positions included in the *EarlyStart Diagnosis Support* framework, but these have yet to be put in place. Evaluation of these initiatives will clearly be required to assess their efficacy.

- The complexity of the current service system can also act as a barrier to many families, as it is often difficult for them to understand and navigate<sup>1</sup>. In addition, some children with developmental delays do not readily meet the specific criteria for any of the current funding models, so may be unable to access either government (disability, health or early special education), or generic early childhood intervention services. There is also a lack of a centralised intake and referral process within each region/area across the state to facilitate families' access to services.

**Recommendations to address current service access inequities and unmet need:**

- 1) That the type and level of funding allocated to a relatively small number of services under the first phase of *Stronger Together* be extended to ECI services throughout the state, to allow all NSW families requiring intervention to have equitable and timely access to the services they need. As a minimum, the level of funding should match the unit cost per child allocated under *EarlyStart*: \$6,500 plus \$1,500 flexible funding to support access to activities and universal services in their own communities that reflect the ordinary experiences in which all young children and their families expect

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<sup>1</sup> The publication by Association of Children with a Disability NSW, *Through the Maze: Information and support for parents of children with a disability in New South Wales* (2008 Edition), has attempted to help families and professionals understand the complexity of service options (both disability-specific and mainstream) for children with a disability in NSW. It can be downloaded at: [http://www.acdnsw.org.au/images/stories/ttm\\_final%20version\\_acr06.pdf](http://www.acdnsw.org.au/images/stories/ttm_final%20version_acr06.pdf)

to participate. A corollary to this is to provide service organisations with budget predictability and timely allocation of funding to meet families' needs.

2) That particular focus be given to addressing access issues relating to:

- The complexity of the service system acting as a barrier to families
- The long waiting lists that are a constant issue throughout the state
- Service provision for those who currently 'slip through the net' of funding categories i.e. where evident delays exist, but a diagnosis remains unclear
- Under-representation of particular groups in services. For example, families from CALD backgrounds, Aboriginal backgrounds and families with complex needs
- Practical aspects such as supporting families' travel needs: In rural areas, some families need to travel vast distances to access ECI services; and in urban areas, a lack of transport can present a significant barrier to some families' ability to access a centre-based service (and services themselves often lack the resources to offer a regular home-visiting programme).

**(b) Variations in service delivery, waiting lists and programme quality between:**

**(i) services provided, or funded, by ADHC**

An integral part of early childhood intervention is to provide timely, specialised support and information to families, in a sensitive and responsive manner. Such support and information is currently made available in a variety of ways, depending on how and when families enter the service system. The timing of a child's diagnosis (under 12 months, or between 1 - 5 years of age) has implications for entry points into the system<sup>2</sup>. Children under 12 months typically have a more straightforward referral pathway, whereas for those between 1-5 years old, entry to the current service system can be 'hit and miss':

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<sup>2</sup> *Disabilities Pathways Project: Mapping Information and Support for Parents of Children with a disability (antenatal to 5 years)* (Inner West Area, 2005). Funded by Families NSW, managed and auspiced by DADHC Metro South Region

- As a result, families need a more systematic and supportive approach to providing them with choices and accurate information *as soon as they have a concern about their child's development*. While there is an existing initiative, the Early Childhood Intervention Infoline, which may be an early point of contact for some families, this is not an advisory service, but can provide only a broad list of potential services, whose listing may not always be up-to-date.
- ADHC's own *Information & Referral* lines would not commonly be accessed by families of young children who are seeking early advice and information regarding their child's development. Anecdotally, it is evident that staff responding to such enquiries, have skills that focus on the needs of adults with disabilities. Targetted training for ADHC *Information and Referral* staff is necessary, so that concerns regarding follow-up for young children, can be addressed more accurately and comprehensively.
- In terms of subsequent service availability, ADHC Regional offices no longer have specialist teams for ECI due to internal restructuring. While this may have had structural benefits, the expertise of ADHC therapists to support very young children, has been compromised, perhaps reflected in anecdotal reports that ADHC staff are not seeing many babies, despite the general imperative to intervene as early as possible when delays are identified. It is also notable that almost all ADHC teams employ only therapists, which is in significant contrast to the ADHC-funded ECI sector, where early childhood special education teachers are recognised as having a particularly important role in the provision of holistic ECI.
- While non-government agencies (funded by ADHC) frequently have more flexible entry criteria to their services when a diagnosis is unclear (funding constraints allowing), entry to ADHC services is limited to children who have a delay in more than one area of their development. Waiting lists for ADHC services appear to be long, based both on reports from families and information shared through professional networks.

- A current significant variation in service provision is that relating to funding availability for children diagnosed with Autism Spectrum Disorder, mostly as a result of Federal initiatives, but with a state-based element adding to the emphasis on this particular disability. While any increase in funds for ECI programmes for children and families is welcome, the fact that it is restricted to a single diagnostic category is creating major inequities in the levels of information, intervention and general support available to families of children with and without autism. Many children with disabilities and their families have complex needs, so to base such funding distinctions solely on a diagnostic category, rather than demonstrated individual need, is difficult to understand. As a result, many families feel their own and their child's needs are being disregarded, while the generic ECI organisations charged with offering support to all, regardless of the cause of a child's delayed development, have been faced with significant ethical dilemmas regarding the differential service levels they are able to provide when these are based on funding source, rather than relative need.

**(ii) ADHC Regional Areas**

- There are significant variations in service delivery across ADHC Regional areas. The *Stronger Together* initiatives such as *EarlyStart* and *Therapy Transition Program*, described earlier, are available either only in some ADHC Regions, or in limited areas within them, which has resulted in there being some very major service gaps for most rural regions. As already described, funding distribution has not been equitable, with the effects of this more critical outside of metropolitan Sydney. One illustration is that even when families are prepared and able to travel, there are some parts of NSW which are not included under existing ADHC Regional funding agreements for ECI services (e.g. Mudgee).
- Models of service delivery must of course reflect local need, so effective consultation at a regional level is essential before implementing new initiatives, or making changes to



existing service provision. An example of a recent pilot project where this does not appear to have occurred is *EarlyStart Diagnosis Support*, initiated under *Stronger Together* to provide early information and support for families. It is still in the early stages of development, but indicators from the field suggest this approach may be necessary to a greater or lesser extent in some locations and circumstances than others, particularly where there is already strong local knowledge about available services for young children and families (frequently the case in rural and regional areas). Generic ECI services often undertake a very similar role to that defined for the *EarlyStart Diagnosis Support* workers, especially given a significant number of families are already attending an ECI agency prior to receiving a diagnosis for their child. In these instances, it is the ECI staff who build relationships with and support the family to and through the diagnosis. Thus in some areas, this model is resulting in a duplication of services.

- One funding initiative under *Stronger Together* that was locally responsive was the *Extending Early Childhood Intervention Initiative (EECII)*. Those organisations in receipt of this funding have been able to build their capacity to provide more flexible, responsive services to a greater number of families. While also not distributed equitably across the state, *EECII* funds were secured by a greater number of services than *EarlyStart*. The case study below illustrates the enormous benefits that have resulted from the injection of additional funds to one regional service:

Receiving funding under the *EECII Extending Services* programme has completely changed the face of this regional ECI service in terms of building capacity, extending the service to the more disadvantaged families in the community, increasing flexibility of service provision models and increasing early identification of delays by other local service providers for young children. The number of families able to receive a service has increased from 50 to 80, and they can now each access a wider variety of programmes within the service, instead of being restricted to either a weekly group, or fortnightly individual session. Family support and education is now widely available. The *EECII* funding has also enabled the service to partner with 8 other services providing various programmes to disadvantaged families (including, but not limited to those from an Aboriginal background). The provision to purchase a vehicle has allowed the ECI service to provide some of its programmes alongside these partner agencies and work within settings where families are already engaged.

- Access to professional staff such as therapists and early childhood special educators, particularly in rural and regional areas, remains difficult for many families. This is a result of a number of factors, including:
  - the general challenges in recruitment and retention of well-qualified professional staff, partly reflecting the output and availability of relevant graduates, as well as the greater or lesser perceived desirability of working in particular locations;
  - the additional restriction on the NGO, ADHC-funded disability sector, which finds it very difficult to compete with the significantly higher salaries and associated employment conditions prevailing in the public sector – their funding levels simply preclude being able to match these;
  - a relative lack of collaborative arrangements between the health and disability sectors (government, NGO and private practitioners) that might result in more flexible service options for families, as well as potentially offering more attractive, professionally supported employment options for staff.

**Recommendations to address issues of concern regarding service delivery across the state:**

- 1) An injection of targeted capacity-building funds for ECI services across NSW to provide all families with access to the full range of supports and services they require within their local communities for themselves and their young children with disabilities (regardless of diagnosis).
- 2) A focus on strategies that will attract well-qualified staff to the NGO ECI sector (which includes being able to offer remuneration similar to that available within directly Government-provided disability, health and education services).
- 3) State-wide consultations with ECI providers before introducing new initiatives, to ensure a good fit with local needs in each region / area.

**(c) flexibility in client funding arrangements and client focused service delivery**

- In early childhood intervention, a family-centred approach has been widely implemented for many years, being promoted and supported by the ADHC training publication *Partners: Recommended Practices in Family-centred Early Childhood Intervention*; and complemented more recently by *Partners for Managers: Managers Module for the Partners Package*. An integral part of this service philosophy is to provide timely, specialised support and information to families, in a sensitive and responsive manner. By focussing on the needs of the whole family during the early years, family-centred practices boost family resilience because they:
  - place families in central roles in decisions and actions
  - are based on family priority and preference
  - support child learning opportunities
  - provide parenting supports and education
  - mobilise informal and formal community supports
  - strengthen existing capabilities
  - promote child and family competence
  - provide specialist resources in response to family-identified need.<sup>3</sup>
- A positive feature of some of the service funding under *Stronger Together* has been the inherent flexibility, and hence increased level of responsiveness to individual child and family needs that it allows.
- A key to this capacity to be so responsive in the case the *EarlyStart* programme, is that ADHC-funded organisations' *Service Description Schedules* have been more flexible, resulting in services that reflect individual, family and community needs. This has enabled recipient organisations to expand their service contexts and provide better support for

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<sup>3</sup> Dunst, C.J. (2000). Revisiting 'Rethinking early intervention'. *Topics in Early Childhood Special Education*, 20, 2, 95-104

general community inclusion, transitioning to universal child and family services (playgroups, community groups, early childhood services, schools) and building partnerships with services to which families are already linked. This has offered families (including those who are traditionally under-represented in ECI service access) a greater choice both of service types and the contexts in which they occur. Some examples include being supported to more readily participate in everyday activities such as swimming lessons, general early childhood programmes, other leisure pursuits and family shopping expeditions.

- A critical additional component has been the availability of a small amount of flexible funding, which families can use (with assistance, if required) in a wide variety of ways to support their access to universal services or community activities. Some such items have included paying for additional pre-school support; the purchase of a 2-child pram so that a parent could transport both her children to local community activities and pre-school; and funding a specialist communication and technology assessment, to assist with a child's inclusion in a mainstream education setting.
- The responsive, client-focussed service approaches outlined above, might be expected to contribute to overall family well-being, as well as an improved readiness and ability to participate in controlling their own intervention supports. These factors have been shown to enhance outcomes for young children with disabilities and their families<sup>4</sup>.
- More universally across ECI (and school-aged) services, the *Family Assistance Fund (FAF)* has been an encouraging initiative in offering some additional flexibility in client funding. It has provided families with \$2,000 per financial year, to meet their individual needs. This small amount of individualised funding has provided families with the opportunity to have greater control to meet the immediate needs of their child and family. Although there are inconsistencies in the application of the *FAF* business rules across the

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<sup>4</sup> Guralnick, M. (Ed) (1997) *The Effectiveness of Early Intervention*. Baltimore: Paul Brookes Publishing

state, the initiative has been positive overall. The scheme is available to families of children with a disability under 18 years old. ECI services have reported that they are supporting many families to apply for *FAF* and that although this process is time-consuming, the initiative is a positive one for families.

**Recommendations to support flexibility in client focussed service delivery:**

- 1) That there is sufficient provision of funding to all services to enable individual needs to be met in a flexible, community-focussed manner.
- 2) That Service Description Schedules for ADHC-funded services reflect this need for flexibility, if individually responsive, client-focussed services are to be available to all.

**(d) compliance with Disability Service Standards,**

- Within the ECI sector there is a clear indication that the Disability Service Standards are a well-used and practical tool for organisations and families. When the current Standards were first released, the interpretative and support materials associated with them reflected a very adult service orientation, and were not user-friendly in relation to issues concerning children with disabilities, their families and the services that support them. This was later resolved with the development of the *Children's Standards in Action*, prepared by ADHC, with input from the sector, to reflect its needs and concerns.
- It is important to note that within the Standards, there are some benchmarks that can be difficult for service providers to attain, as a result of external factors such as funding limitations. Examples include:
  - *Standard 1* (Standard Service Access). Limitations in funding mean that families are not assured of equity in service access across NSW. Waiting lists are common.
  - *Standard 5* (Participation and Integration). Many community support options that families would like to access for their child and/or family are beyond the support

capacity of most ADHC-funded ECI organisations (the funding and staffing resources are simply not available; and some restrictions on the way in which funds may be used can create a barrier).

**Recommendations regarding the further review of the Disability Service Standards:**

- 1) That the role of family relationships be included in the Standards.
- 2) That Standard 10 (Rights and Freedom from Abuse) not be removed from the Standards.
- 3) That the *Children's Standards in Action* support materials continue to provide an appropriate framework for children with disabilities and their families.

**(e) adequacy of complaint handling, grievance mechanisms and ADHC-funded advocacy services**

- Based on our knowledge of ECI organisations, all services would have effective mechanisms for complaint handling and grievance mechanisms. However, we recognise that families are vulnerable in the early years and that throughout the diagnosis and intervention period, they are often overwhelmed with the practical issues they are dealing with. Therefore, they may not have the ability, strength or resources to make complaints at this time.
- ADHC-funded advocacy services are predominantly adult-focussed. Some organisations do provide disability-specific supports to families with young children (for example, Down Syndrome NSW). However, many children do not have a specific diagnosis and so are not eligible for services from such organisations. The only recourse currently for most families with service-related concerns that are not resolved at the local level, is either through the Ombudsman, or Anti-Discrimination Board.

### **Recommendation regarding advocacy:**

- 1) We recommend that advocacy organisations be supported to expand their service expertise to the concerns of families with young children.

### **(f) internal and external program evaluation including program auditing and achievement of program performance indicators review**

- Overall, the ADHC *Integrated Monitoring Framework (IMF)* was viewed as an opportunity for useful feedback by funded organisations. It was, however, a very intense process that focussed essentially on documentation around governance, management systems & processes, workforce development, service provision policies and service networks / partnerships, rather than addressing issues of quality, innovation and best practice. Organisations have reported that they would like more opportunities to show the depth and breadth of their services, without creating a more onerous process.
- As already noted, there have been some improvements to the *Service Description Schedule (SDS)* requirements under which all ADHC-funded ECI services must operate. While these still include some generic statements that do not always relate meaningfully to specific service functions, they have become more detailed and mostly reflect evidence-based practice within the ECI field. Further developments in this direction would provide organisations with a clearer, but necessarily flexible frame-work within which to provide their funded services.
- An additional issue for the ECI sector in relation to their *SDSs* is the inconsistency in the description of outputs: some are expressed in numbers of children receiving services, while others specify the number of hours of service delivery.
- ADHC's implementation of the collection of *Minimum Data Set (MDS)* statistics required under the Commonwealth-State Disability Agreement has presented particular difficulties for ECI services. The service types specified and general data categories provided reflect

adult-focussed services, which do not fit well for those programmes offered to families of young children: many aspects of ECI service delivery cannot be acknowledged or recorded easily in this system. Only very recently, after much feedback from the ECI sector to ADHC over several years, has there been agreement on a clear definition of exactly which elements of service delivery constitute reportable data. Still unresolved is the issue of matching *MDS* outputs with those specified in a service's *SDS*. As a result of these issues, it is very doubtful that any statistics generated would provide meaningful information in relation to service planning and/or funding.

### **Recommendations regarding programme evaluation for the ECI sector:**

- 1) That any monitoring framework reflect and promote the key elements of providing quality ECI services, based on recognised best practice, in addition to cross-sector statutory requirements.
- 2) That *Service Description Schedule* outputs are consistently expressed across the ECI sector, to allow more meaningful evaluation of services.
- 3) That the *Minimum Data Set* process be modified to reflect more accurately the ECI sector's particular service delivery components.
- 4) That all developments in programme evaluation and performance measures involve prior, in-depth consultations with all parts of the disability sector, including ECI, so that the specific needs of each are addressed.

### **(g) any other matters.**

- The issues faced by families in the early years are challenging and very different to those they will face as their child grows up. Identification, diagnosis, getting to know what disability services can offer, and being supported at the beginning of their journey through quality early childhood intervention programmes, are unique to this time. To reflect the



critical importance of this life stage in setting positive foundations for child and family well-being, it is evident that ECI needs more explicit recognition within ADHC reform initiatives. It was notable, for example, that the recent ADHC Consultation Paper regarding implementation of the second phase of the *Stronger Together* agenda contained minimal reference to ECI-related issues in its background content; and the recently-released report of the Industry Development Fund, *NSW Disability Services Sector: Directions for Industry Development* focussed almost exclusively on the needs of adult disability services, despite significant attempts by the ECI sector to have its voice heard. This relative 'invisibility' of ECI issues is also often evident in ADHC Budget papers, report cards, etc.

- If families of young children with disabilities and delays throughout NSW are to be provided with quality ECI services that can be responsive to their changing needs and expectations, the particular support needs of the ECI sector must receive appropriate recognition. As the peak body for the ECI sector, ECIA NSW Chapter is well-placed to provide significant and informed input to all developments affecting services for young children with disabilities and their families.

### **Recommendations:**

- 1) That the critical importance of the early years receives explicit, informed recognition in all ADHC-funded disability sector-wide initiatives and reports.
- 2) That ECI sector-specific consultations occur regularly, so that the particular issues affecting service access and provision for young children and their families may be addressed.