LEGISLATIVE ASSEMBLY FOR THE
AUSTRALIAN CAPITAL TERRITORY

REPORT ON THE

INQUIRY INTO

EARLY INTERVENTION SERVICES FOR

DEVELOPMENTALLY DELAYED AND DISABLED CHILDREN

REPORT NO. 6

OF

THE STANDING COMMITTEE ON SOCIAL POLICY

June 1994

RESOLUTION OF APPOINTMENT

The following general purpose standing committees be established to inquire into and report on matters referred to it by the Assembly or matters that are considered by the committee to be of concern to the community ...

... a Standing Committee on Social Policy to consider matters related to health, hospitals, nursing homes, welfare, employment, housing, social security, the ageing, people with disabilities, the family, Aboriginal people, youth affairs, the status of women, multicultural affairs, industrial relations, occupational health and safety, education, the arts, sport and recreation.

Minutes of Proceedings, (1992), No. 1, 27 March 1992, pp 5,6.

TERMS OF REFERENCE

That the Standing Committee on Social Policy:

(1) inquire into and report on the provision of early intervention services to children of 0-5 years in the ACT who have been identified as experiencing developmental delays and/or disabilities of any kind, including:

   (a) the philosophical premise and/or model which underlies the provision of services;

   (b) the extent and frequency of availability of services;

   (c) gaps which can be identified in the provision of services with regard to the range of services available and the severity of disabilities of the children concerned;

   (d) the degree to which the provision of services is integrated and co-ordinated;

   (e) the desirability of incorporating conductive education into the range of early intervention services available to children;

   (f) any related matters which may arise; and

(2) the Committee is required to report to the Assembly by the last sitting day of June 1994.

Minutes of Proceedings, (1992-93), No. 82, 21 October 1993, p.466

COMMITTEE MEMBERSHIP

Ms Annette Ellis (Chair)

Mr Michael Moore (Deputy Chair) *(from 16 March 1993)*

Mrs Kate Carnell

Mr Greg Cornwell

Mrs Ellnor Grassby

Ms Helen Szuty *(to 16 March 1993)*

Secretaries: Mr Kim Bond *(to 4 March 1994)*

Mr Russell Keith *(from 4 March 1994)*

PREFACE

Early intervention is a developing area. The disability service area in Australia is still working through the transformation from institutionally based to community based services that has occurred in the preceding decades. That same time has also seen great developments and increases in the quality and types of early intervention programs.

Early intervention services around Australia are in various stages of integrating the various programs they offer and developing more holistic approaches to helping children with developmental delays or disabilities. Different jurisdictions have taken different approaches to, and are at different levels of, integration. A dominant theme in the integration of services is the case management approach.

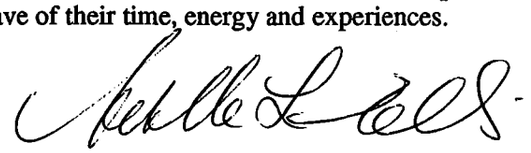
It was evident to the Committee that early intervention services in the ACT were run by dedicated professionals who were providing a valuable service to families with a developmentally delayed or disabled child. It was also clear that the ACT had work to do to provide the type of coordinated, efficient, holistic services required by society today. That work was mainly to be done in changing the administrative structures.

The Committee considered that the present administrative structure was inefficient, mitigated against service integration, and was philosophically out of step with current understanding of disabilities.

The Committee also found that funding for early intervention services was inadequate. As outlined at 3.51. in the Report, the Committee wished to avoid making recommendations relating to funding. The Committee is aware that the Government has limited resources. The Committee also believes that better services need to be provided through working more efficiently and has made recommendations towards that end. The Committee found, however, that the funding for this vital area of community service had fallen below an acceptable level.

The Committee received 29 submissions to its inquiry and spoke to numerous parents and service providers. The Committee was aware that both parents of developmentally delayed and disabled children and their service providers have enormous pressures on their time, energy and emotions and appreciates the effort that went into preparing submissions and speaking to the Committee.

I would like to thank all of those who helped the Committee in its inquiry and gave of their time, energy and experiences.



Annette Ellis MLA
Chair
10 June 1994

TABLE OF CONTENTS

ACRONYMS/ABBREVIATIONS

ADACAS	ACT Disability Aged and Carer Advocacy Service
CHADS	Child Health & Development Service
CHMO	Child Health Medical Officer
CIS	Country Infant Service
DEET	Department of Employment, Education & Training (Commonwealth)
DET	Department of Employment & Training (ACT)
EI	Early intervention
EIS	Early Intervention Services
FBI	Friends of the Brain Injured
FTE	Full time equivalent
H&CSB	Housing & Community Service Bureau
HIB	Haemophilus Influenzae Type b
NHMRC	National Health and Medical Research Council
OT	Occupational Therapy/Therapist
PT	Physiotherapy/Physiotherapist
QE II	Queen Elizabeth II Hospital
SP	Speech Pathology/Pathologist

SUMMARY OF RECOMMENDATIONS

Recommendation 1

3.15. The Committee recommends that responsibility for all children's services come under a single administrative unit which is not in the Department of Health.

Recommendation 2

3.43. The Committee recommends that the Government provide a case management service to families with a developmentally delayed or disabled child appropriate to the needs of the individual family.

Recommendation 3

3.49. The Committee recommends that the ACT Government introduces a client purchasing model for early intervention services whereby services are purchased from service providers on behalf of the client according to a program agreed to by parents and their case worker.

Recommendation 4

3.54. The Committee recommends that the ACT Government increase its funding for early intervention services to a level where they can meet at least the basic therapy and respite care needs of their clients.

Recommendation 5

3.61. The Committee recommends that the Government conduct a parent based evaluation and consultation on establishing a parent, community experts and government representative board of management for Child Health and Development Services Early Intervention Services. The Committee also recommends that decisions about the constitution, role and responsibility of this board be determined by the appropriate minister.

Recommendation 6

4.26. The Committee recommends that the ACT Government provide funding for one conductor and one part time preschool teacher for a pilot program run on the principles of conductive education. This funding should not come out of funding for existing early intervention services.

Recommendation 7

4.27. The Committee recommends that the ACT Government commission a study of the pilot program by an objective body capable of producing a study which would meet the standards of the scientific and medical community.

Recommendation 8

4.29. The Committee recommends that the ACT Government provide for the registration of conductors as teachers in the ACT.

1. EARLY INTERVENTION SERVICES IN THE A.C.T.

1.1. Early intervention services in the ACT are primarily provided by the ACT Government through the Department of Health, the Department of Education and Training, and the Housing and Community Service Bureau.[1] Services are also provided by a number of non-government agencies and parent and community groups. These include Noah's Ark, the NSW Spastic Centre, the NSW Royal Blind Society, the Friends of the Brain Injured, the Down Syndrome Association, the Autistic Association, the Epilepsy Association, Fabric Inc and Regional Community Services. There are also services of a more general nature provided by government and non-government agencies which are of relevance to early intervention, such as services provided by hospitals, health centres, the Child and Adolescent Mental Health Service, the Queen Elizabeth II Hospital and Barnardos Australia.

Government Services

ACT Department of Health

1.2. The Department of Health provides nearly all Government early intervention services for babies and is generally the primary service provider until a child reaches preschool age.

1.3. ACT Health offers multidisciplinary therapy through the Child Health and Development Service's (CHADS) Early Intervention Service (EIS)[2]. CHADS EIS provides a multidisciplinary service employing physiotherapists, occupational therapists, speech pathologists, social workers and medical officers for children from birth to school entry with, or at risk of, developmental delays or disabilities. CHADS also provides community speech pathology, physiotherapy and occupational therapy on a single discipline basis. These services provide assessment, treatment, home programs and consultancy services. ACT Health also employs Child Health Medical Officers who provide medical assessments and referrals.

1.4. ACT Health also runs the ACT Equipment Scheme which provides assessment, acquires equipment and offers some financial assistance to families to enable them to acquire specialised equipment for personal use.

1.5. The table at Appendix 6 sets out the specialist early intervention services provided by ACT Health.

---

1 Information about Government services in this chapter is mainly drawn from the ACT Government's Submission (Submission No. 16)

2 To avoid confusion between early intervention services in general and the Child Health and Development Services Early Intervention Service, the latter will be referred to as EIS from this point.

Department of Education and Training

1.6. The Department of Education and Training (DET) provides, as a joint program with CHADS EIS, a playgroup for children from 18 months to three years of age. DET also provides a range of programs for children over three years of age.

1.7. The Services provided by DET include the following:

- **Early Intervention Services Playgroup** — This provides a weekly educational program in a playgroup setting for children with, or at risk of, developmental delays or disabilities from 18 months to three years of age. Home visits and parental involvement in the service are encouraged. In November 1993 the playgroup had 72 students and four full time equivalent (FTE) staff.
- **Early Intervention Units** — Provides a preschool-like education program in small classes of up to 12 children three to five years of age, located at five different preschools. Eligibility is as for EIS Playgroup. In November 1993 the Early Intervention Units had 120 students.
- **Special Schools** — Malkara, Cranleigh and Turner Special Schools offer small structured group programs to children from 3 years of age. Eligibility is the same as the EIS Playgroup. Integration is encouraged and many children attend sessions in mainstream preschools each week. Children may attend up to 10 sessions per week and transport is provided if required. Children at Malkara and Cranleigh receive consultations from Community Disability Services regarding individual programs, and children at Turner receive consultation from CHADS EIS. At November 1993, the special schools had 82 students in total.
- **Autistic Unit** — This unit provides a specially structured program for children from three to eight years of age with a diagnosis of autism. Transport is provided if required. At November 1993, the unit had eight students.
- **Language Preschool** — This program provides children from three to five years of age with specific delays in speech and language with two or four sessions per week, jointly run with a CHADS speech pathologist. At November 1993, the preschool had 22 students.
- **Itinerant Teaching Service for Hearing and Vision Impaired Children** — This service provides children from any age with a diagnosed significant hearing or vision impairment with a program for the child and family in their home and in integration settings; support for the child in preschool; and consultation to assist in the child's wider activities. At November 1993, the service provided for 24 hearing impaired children and 6 with a vision impairment.

1.8. The table at Appendix 7 sets out the specialist early intervention services provided by the Department of Employment and Training.

Housing and Community Service Bureau

1.9. The Community Disability Services provides multidisciplinary services for children and adults with a disability. In the context of a broadly based specialist disability service, the team provides early intervention services for children with significant delays in development, most of whom are three or more years of age and attend Malkara or Cranleigh Schools. Individual programs, behaviour intervention, case management and consultancy are provided with programs which vary according to client needs. There is regular liaison with education special school staff.

1.10. The multidisciplinary team is comprised of physiotherapists, occupational therapists, speech pathologists, social workers and psychologists. The team spends part of its time working in early intervention; the remainder is spent with older children and adults.

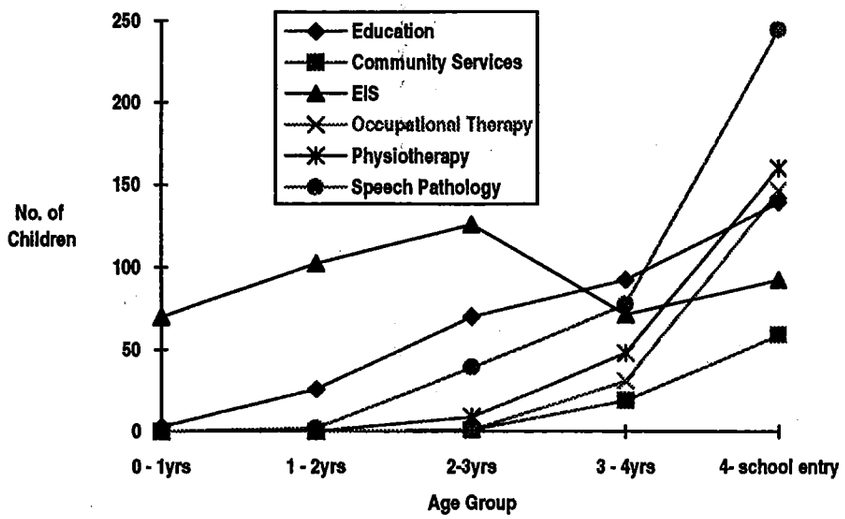
1.11. The Community Support Team has a respite care service, Birralee Hostel, which is used by families who have a child with an intellectual disability or developmental delay. Families can book their child in for respite care for up to seven days a month, although the service is in heavy demand and has a waiting list. There is also a system for assisting with emergency respite care. Birralee staff liaise with the special schools, and other services on a regular basis. The team also administers the recreation program for people with disabilities which assists clients by providing additional respite in the form of holidays, camps, general recreation programs and outdoor adventure programs.

1.12. The Bureau also runs the Independent Living Centre which provides advice to families and service providers on equipment for disabled children.

1.13. The table at Appendix 8 sets out the specialist early intervention services provided by the Housing and Community Services Bureau.

1.14. The use of ACT Government early intervention services, broken down according to the agency service and age is illustrated at Figure 1 below.

Figure 1: Use of Government Services By Age Group



NB: EIS, Occupational Therapy, Physiotherapy and Speech Pathology are all provided by ACT Health

Non-Government Services

Noah's Ark

1.15. Noah's Ark was established in 1973 to provide a toy library for handicapped children. It's service's now include:

- physiotherapy and occupational therapy and assessments for children with learning difficulties;
- integrated playgroups;
- a parent and professional reference library; and
- a toy library, which includes educational and therapeutic aids.

1.16. Noah's Ark also has a mobile resource unit.

1.17. Noah's Ark is a non-government organisation. It is funded by government grants, donations and fees for services.

Spastic Centre (NSW)

1.18. The Spastic Centre is a non-government organisation that provides a range of services for people with cerebral palsy or an allied condition. The Centre provides a Country Infant Service (CIS) in Sydney which is accessed by a number of ACT residents. The CIS is a week long live-in service developed to give country families the opportunity to learn about the management and

treatment of their child, to help them understand their child's needs and to offer ongoing support and assistance.

Royal Blind Society (NSW)

1.19. The Royal Blind Society provides services to vision impaired and blind children through its Child and Adolescent Service, an itinerate multidisciplinary team based in Sydney. This is a family centred, home based service which aims to enable the child to remain with his or her family and utilise the generic services within the community. The service also provides consultative services to such generic services.

Friends of the Brain Injured

1.20. The Friends of the Brain Injured (ACT) runs the Canberra Centre for Conductive Education. This Centre provides a class for children aged between 18 months and five years run by a conductor who has graduated from the four year course provided by the Peto Institute in Hungary.

Regional Community Support Workers (Integration Teams)

1.21. Regional Community Support Workers provide a link between families who have a child with addition needs (ie, children with a disability or from a non-English speaking background), the community, resource agencies and children's services. Teams are based in Tuggeranong, Weston, Woden, Southside, Northside and Belconnen Community Services.

Technical Aids to the Disabled

1.22. Technical Aids to the Disabled is a voluntary organisation dedicated to designing and making special aids for disabled people which are not available commercially.

Family Based Respite Care Inc (Fabric)

1.23. Fabric provides respite care for families with a person with a disability under the age of 25. Such care is usually provided in the home of the family. Families are allotted a certain number of hours within a four week period, following consultation with the coordinator. Fabric is funded by government grants and family contributions.

Queen Elizabeth II Hospital

1.24. Queen Elizabeth II Hospital provides:

- transitional care in relation to parenting and associated issues when the disability is diagnosed at or shortly after birth;
- a 24 hour phone advice and support service in relation to parenting and associated issues;
- assistance in establishing and maintaining feeding, either breastfeeding or artificial, and the introduction of solids;

- assistance in establishing and maintaining an appropriate routine by providing the family with settling strategies;
- ongoing support and guidance; and
- crisis support care or 'time out care' for families by staff with expertise in the management of babies with special needs.

Barnardos Australia

1.25. Barnardos operates a program called Temporary Family Care which offers crisis care and regular respite care in the family setting for disadvantaged children from 0 to 12 years of age.

2. PHILOSOPHY OF EARLY INTERVENTION SERVICES

Family Centred Services

2.1. The last fifty years has seen dramatic changes in the way services for children with disabilities have been administered. There has been a fundamental shift from institutionalising people with a disability to supporting those people to live in the community. Hence the objects of the ACT *Disability Services Act 1991* include:

> *to enable persons with disabilities to receive the services necessary to enable them to achieve their maximum potential as members of the community;*
>
> *to enable persons with disabilities to receive services that—*
>
> *(i) further their integration into the community and complement services available generally to persons in the community...*[3]

2.2. Accompanying the shift towards supporting people in the community has come an emphasis on supporting the family as the primary care provider. This has led to family centred services, where services are geared towards equipping the family to care for the child and supporting the family in that care by providing the appropriate therapy, equipment, respite care, financial assistance and other support services.

2.3. This theory is generally universal; its application varies between agencies and individuals.

2.4. In practice, family centred services vary in the extent to which they actively involve parents in the management and delivery of services to the child. The extent to which a parent may be involved in a child's early intervention program depends on a number of factors, including the parent's desire or ability to be involved; the level of information provided to parents; the complexity or specialisation of therapies; and the willingness or ability of service providers to involve parents.

2.5. The Committee considered that it was important that parents be able to freely choose their level of involvement. Parents need to be able to have informed input and participation in their child's intervention program and to be free to participate. The Committee held concerns about parents' ability to achieve both of these aims.

2.6. Concerns about parents ability to be involved are tied to the provision of information to parents, the attitudes of professionals towards parental input, and the ability of management structures to respond to parents. These issues are discussed further at in Chapter 3.

---

3 ACT *Disability Services Act 1991*, s 3.

2.7. Concerns about parents freedom to choose to limit their level of involvement were held because of the enormous pressure parents were often under and the feelings of guilt that can be associated with having a disabled child. Parents may wish to limit their involvement for personal, work, health, emotional, financial or other reasons and need to be able to do so without compromising the future of their child.

Holistic Services

2.8. Over one third of the submissions to the Committee called for more holistic early intervention services. It was a repeated theme in the submissions that people wanted services to take into account all of the needs of the child and to treat the child as a human being, not as 'a leg problem' or 'a speech problem'.

2.9. This call for holistic services was often tied to the need for coordination between and within services, particularly with multi and single disciplinary services. Services which specialised on a particular need of a child needed to be coordinated within a framework that focussed on the child as a whole.

2.10. It was also suggested by some that the philosophical orientation of health services, which was aimed at curing and preventing illness, mitigates against a service being able to take an holistic approach with children with a disability, who need skills for living with their disability.

2.11. As the National Association for Conductive Education (ACT) put it:

> *...it is a question of how traditional "therapy" programs can be integrated as closely and effectively as possibly* (sic) *with programs promoting educative, cognitive, social, emotional and intellectual development. It is a question of how the provision of early intervention services can be modernised to ensure a more holistic "whole of life" approach, with health, education and community service needs all acknowledged to be interlinked.*
>
> *This will never be fully and smoothly achieved as long as "therapy" continues to be seen as a discrete service, separable from educational programs... as long as "physical therapy" is provided separately from other vital components of services for children with disabilities and their families...*
>
> *In our view, assigning major responsibility for the provision of early intervention services to the Health Department - any Health Department - is an anachronism. It reflects the misguided views of earlier generations that disability was essentially a medical issue - that children with disabilities required "treatment". Disability, however, is not an illness. Children with disabilities are not sick* per se, *and early intervention is not about treatment in any medical sense; it is about helping children acquire basic functional living skills they would otherwise not be able to acquire. Children* **learn** *the skills they acquire, as* <u>all</u> *early intervention services now acknowledge.*[4]

2.12. The Committee concurs with the view that early intervention services need to be holistic in the sense that they need to be coordinated in such a way that they take account of the needs of the whole child. For a further discussion of service coordination see 3.30. to 3.43.

2.13. The Committee also agrees with the view that early intervention is not primarily a health issue. For a related discussion of administrative arrangements see 3.1. to 3.15.

---

4 Submission 19, p 2.

3. ADMINISTRATION OF EARLY INTERVENTION SERVICES

Administrative Arrangements of Government Early Intervention Services

3.1. Government run early intervention services in the ACT are administered by three different departments: the Department of Health, the Department of Education and Training, and the Housing and Community Services Bureau.

3.2. Generally, the Department of Health has responsibility for early intervention services for children up to three years of age. For children from ages three to school entry, Health maintains responsibility for therapy services while the Department of Education and Training also provides services through its Early Intervention Units (special preschools for 3 to 4 year olds), the EIS Playgroup, and the Autistic Unit. At school entry, the Department of Education and Training becomes the primary service provider through special schools and the CHADS EIS withdraws services. Therapy services are then provided by the Housing and Community Services Bureau and by CHADS Community therapists.

3.3. The most frequent theme in the submissions to the inquiry was the lack of coordination between services. Parents commented on the lack of coordination between different Government Departments; breaks in continuity of therapy; the disruption caused as their child is passed from one Department to another as he or she developed; and the difficulty in accessing and comprehending information about the services different departments offer.

3.4. One point at which a number of parents felt a lack of continuity between Departments was when their child moved to a special school.

> *Parents feel that their children would benefit by being free to continue to access the more comprehensive individual therapy available through EIS, rather than the present system which cuts them off from EIS when the children attain the age of three years, and begin attendance at one of the pre-schools of Malkara or Cranleigh. Here, they receive group therapy only, which is provided by a totally different Department.*[5]

3.5. This can cause a Catch 22 situation in that it is moderate to severely disabled children who move on to special schools at the age of three, but by moving on, they end up missing out on therapy.

> ...[EIS therapy] *only stops at three if your child leaves the therapy centre and attends one of the special schools, like Malkara... and, yes, we are quite concerned that the individual therapy does stop for children that have, what is it, moderate to severe intellectual and physical disabilities. It really is quite a*

---

5 Submission 3, p 3.

concern and personally—except for lack of money—[I] *cannot see any reason why this individual therapy cannot continue beyond that point.*[6]

I was told a fortnight ago by the Principal of Malkara that therapy is practically non existent through the special schools and ... the majority of kids that do go to the special schools are moderate to severely disabled therefore they need a great deal more than the group therapy that is supposedly offered.[7]

3.6. A number of parents considered that the division between therapy and education cut both ways.

Some children who currently receive therapeutic services need educational services as well, and these are not always provided.

Children who progress to some special schools e.g. Malkara, Cranleigh, experience insufficient/non-existent therapeutic services after this move.[8]

3.7. Parents also expressed the view that there is a need for closer integration in the services provided by the Departments of Education and Health so that their child's education and therapy needs could be met at the same time.

Some consideration needs to given to involving the Department of Education in EIS, so that therapy for children can take into account their educational development from an earlier age. This may help prevent the present fragmented approach.[9]

3.8. Parents also noted that the spread and management of services across Departments caused inefficiencies.

The ACT system is counter productive in its fundamental structure. The Department of Health looks after children up to 3 years of age with the Department of Education taking over from there. As an (sic) *simple example of how this works against the best interests of disabled children, the EIS has no hydrotherapy pool but Cranleigh special school does. There appear to be no formal links between the Department of Education (which runs Cranleigh) and the Department of Health which runs the EIS. Why can't the hydrotherapy pool be used by younger children with severe disabilities who don't attend Cranleigh?*[10]

3.9. One parent said that:

The problems facing parents of disabled children are great enough without having to deal with the present bureaucratic separation of responsibilities between health, education and community services....

6 Uncorrected Proof Transcript, p 7.
7 Uncorrected Proof Transcript, p 8.
8 Submission 30, p 2.
9 Submission 3, p 3.
10 Submission 25, p 4.

At present it is too easy for these children to "fall between two planks". Responsibility for provision of services to disabled children should rest with one Minister and one department. As these children are not sick and their problems usually relate to learning, the logical portfolio would be Education and Training.[11]

3.10. ***The Committee considers that the confusion, gaps in service delivery, inefficiencies and frustration that is caused by spreading early intervention service across three Departments and three Budget programs is unnecessary and that such services should be brought under the one administrative unit.***

3.11. The Committee also notes that the above difficulties are not limited to early intervention services but that other services for children also fall foul of the bureaucratic web stretched between the three departments. This was evident in the case of children at risk of harm from neglect or abuse. Such children and their families often fail to receive appropriate care and support as they fall into the gaps between different agencies' areas of responsibility.

3.12. The most effective solution to this problem would be to draw all children's services into the one administrative unit and for that unit to take an individual case management approach where necessary for children and their families in need.

3.13. Care for Kids in Crisis commented that:

One of the difficulties with departments at the moment is ... where you have children and parents where the department says, "No, I'm not going to handle this. It must belong to somebody else", and you go to the other department and they say, "No, no, it's not ours. It's that one that you just spoke to", and those kids fall right between the cracks, nobody will pick them up, and at least if you had an umbrella of children's services somebody has got to because it is a child.[12]

3.14. The Committee tends toward the view that the most appropriate department to have responsibility for children's services would be the Housing and Community Services Bureau and is firmly of the view that it should not be the Department of Health. The Committee considers that the proper responsibility of the Department of Health is related to illness and that most children's services, including most early intervention services, are not directly related to illness.

3.15. The Committee recommends that responsibility for all children's services come under a single administrative unit which is not in the Department of Health.

11 Submission 27, pp 4&5.
12 Uncorrected Proof Transcript, p 158.

Child Health and Development Service's Early Intervention Service

Frequency of therapy services

3.16. The most frequent comment in relation to the CHADS EIS was that therapy services for many children were too infrequent. There appeared to be a consensus amongst parents that frequency of appointments at EIS was more closely tied to availability rather than need. The overwhelming majority of these concerns were expressed by parents who had children with a moderate to severe disability. Families with more mildly affected children may not have similar problems.

3.17. Most parents were pleased with the therapy their children received and the quality and dedication of the professionals providing the therapy, but many parents considered that the therapy sessions were too far apart to be of maximum benefit or felt uncomfortable in the belief that, if for some reason their child was to require more therapy, it would not be available.

> *In our opinion, Callum was assisted by dedicated professionals, who are overworked and spread too thinly... Callum only sees his speech pathologist at 6 to 8 week intervals. This is not enough... The occupational therapists are also short staffed, and waiting times for appointments may also be 6 to 8 weeks. This can mean only 6 appointments a year for a child that needs a lot of help... Callum saw his physiotherapist more regularly, but the physios and OT's often had to share a room with another therapist of the same discipline which was unproductive for children, such as Callum, who were easily distracted... I understand that there are only 2 social workers at the EIS who are responsible for all the families of children in Canberra. They are incredibly overworked. This is probably true for* [his doctor] *as well.*[13]

> *I was not unhappy with the frequency of therapy visits for my son but was aware that there was no flexibility for more frequent visits had the need arisen. The feeling I got was the therapists were under-staffed and over-worked and they were doing the best they possibly could but there comes a time when* ***that is not enough.***[14]

3.18. CHADS indicated that despite resource constraints, therapy was provided according to need, noting that different children will have a wide range of needs. Figures provided by the Government indicated that over 5% of children received weekly therapy and that, unless under review, no child receiving therapy will be seen less than monthly. In contrast to this, most parents giving evidence to the Committee who wanted more therapy for their child indicated that they were receiving particular therapies only around six weekly.

13 Submission 4, p 2.
14 Submission 8, p 2.

3.19. Government figures showing frequency of various therapy visits are at Appendix 9.

3.20. There was a belief expressed by a few witnesses that EIS would give more therapy for children with a milder disability with whom there was a greater likelihood of a positive outcome. Some parents said that EIS felt uncomfortable or did not know how to handle children with more severe disabilities. Although no empirical evidence was given to support this view, it was consistent with the amounts of therapy being given to the children of parents giving evidence to the inquiry.

> *I quote from a mother whose child was born prematurely at 30 weeks gestation and now has cerebral palsy with spastic quadriplegia:*
>
> > *"in the Canberra Therapy Centre.....they just clearly do not have the expertise and knowledge, experience of the problems of cerebral palsy.....even quite basic problems really."...*
> >
> > *"....they basically concentrate on the really mild ones because they can actually do something for them, and they actually see some results. The more severe ones like my little boy.....they basically have nothing at all to offer.....an hour every five weeks for a child with..(child)'s physical problems....."*[15]

3.21. The infrequency of appointments due to the high case load of therapists also resulted in feelings of isolation of parents as they did not feel able to approach their therapists about problems or difficulties they were having with their child between appointments. Although parents acknowledged they were able to telephone their therapists and ask questions, they expressed a reluctance to do so due to the therapists already high workload.

Continuity of therapy services

> *...as you have heard from people that—it is continuity, I think, that is the most important thing and that is the thing that you will probably find can be very lacking at times.*[16]

3.22. Tied to the frequency of therapy services at EIS, the Committee heard of numerous incidents of breaks in the continuity of services. Breaks in continuity were caused by:

- therapist being on recreation or maternity leave;
- the child missing an appointment, eg, due to illness, and unable to make a substitute appointment;
- changes in therapy staffing not being communicated effectively to parents and resulting in missed sessions; and

15 Submission 11, p 2.
16 Uncorrected Proof Transcript, p 73.

- changes in therapy staffing interrupting the therapy program.

3.23. The Committee was astonished to hear that it was usually not possible to replace therapy staff who went on recreation and maternity leave because the Department of Health had tight budgetary constraints. It was also explained that there were a limited number of therapists in the ACT and it was difficult to recruit both casual and permanent staff.

> *I have to say that you know that ACT Health has budget problems and we, in the last year, notwithstanding the fact that it is known that ACT Health has over expended its budget this year, ...have had to take whatever management strategy we can to reign in our expenditure. This means that, in terms of back-fill arrangements for staff, we do not have the funds to do it and, when we have a problem with meeting our allocation, then there are certain things that we cannot do.*[17]

3.24. The Committee was informed that during periods when a therapist would be absent for reasons such as recreation or maternity leave, that therapist would arrange for other therapists to manage individual cases during her absence as appropriate. It was evident from comments made by parents that this system was not satisfactory as all therapists were carrying a very heavy caseload. Parents' inability to arrange substitute appointments when necessary is also indicative of an excessive case load.

3.25. The breaks in continuity associated with changes in staffing indicated communication difficulties within EIS and between EIS and parents.

3.26. Some parents also complained that there was a lack of continuity between different sessions from the same therapist. This appeared to be due to the infrequency of appointments and the therapist's case load.

Information on other services

3.27. Over a third of the submissions to the inquiry commented on the lack of information about the services available for developmentally delayed or disabled children and their families. It was also considered that, as EIS was usually the first point of contact with services dedicated to such children and was the major service provider for very young developmentally delayed or disabled children, EIS should inform parents who have a developmentally delayed or disabled child of the range of services available.

3.28. Ignorance of services available appeared to be widespread. Parents commented on the length of time it took for them to find out about other services provided by CHADS, services provided by other Government agencies, support service and groups, and alternative therapies.[18]

17 Uncorrected Proof Transcript, p 120.
18 See for example: Submission 8, p 1; Submission 27, p 4; Uncorrected Proof Transcript, p 65

3.29. A number of parents also commented on the negative attitude of staff members at EIS towards alternative therapies, such as conductive education and osteopathy. Some parents had been told explicitly or implicitly that use at such therapies could affect the provision of service at EIS.[19]

Coordination of therapy services

3.30. A number of witnesses commented that there was a lack of coordination within the multidisciplinary approach of EIS. It was considered that one therapist would not know what another one was doing with a child, much less have an integrated approach to the child's needs.

3.31. Some parents commented on the lack of any kind of case management whereby the child's overall needs would be assessed. Instead they felt that individual therapists would be addressing particular problems but that no-one was taking care of the whole child.

> *As time went by we became increasingly frustrated with the service available from the Centre. We could only have access for one hour every six weeks and we had to see different people for occupational therapy, speech therapy, and physiotherapy. Whilst each of the staff came across as caring and concerned, no one person had a complete picture of David's condition.*[20]

> *We would like to see somebody who could be a contact for the family. You might have seen multiple speech therapists in a two year period. You might be in a situation where you suddenly think, "Well, I've got nobody who knows our story, who knows our child, that I can go and talk to." You can go and see a social worker, but the contact is not there. Somebody who knows the situation, right from the start, can help, to overcome the problem of being overwhelmed.*[21]

The Need for Coordination and Provision of Information

3.32. In evidence before the Committee, a number of parents talked of being unaware that their child had any real problem while, in retrospect, they considered that their therapist or paediatrician had an awareness that not all was well. An extreme case was one family with a very premature baby who recounted that, having been informed for 18 months that their child was developmentally delayed, they were only informed of a diagnosis of cerebral palsy after quizzing their paediatrician. Parents recounted how when they where not given information by their doctors or therapists for fear of distressing them, their only source of information was medical dictionaries which invariably gave the worst case scenario for any condition in very blunt language.

19 See for example: Submission 24, p 1; Submission 8, p 2.
20 Submission 27, p 2.
21 Uncorrected Proof Transcript, p 50.

At the time [of entering EIS] *we didn't have a diagnosis and didn't really think there was anything wrong. Straight away I was unimpressed by the lack of communication about my son's condition and also the lack of information provided for us as parents. We didn't see a social worker and at the time I thought social workers were for other people, not us, and in hindsight we should have had a compulsory appointment with the social worker and resident doctor. The information given about related services such as Respite Care was not forthcoming. Also information about the Disability Allowance for Declan and subsides available for equipment through the ACT Equipment Scheme were never fully explained. This information was related to us by the Independent Living Centre in Weston at one of their open days. The first time I ever heard the term 'hypotonia' in reference to my son was on a report form to the Paediatrician as the 'Clinical Condition'. I had never hear* (sic) *of this and had no idea what it meant and when I asked a therapist for information I was told that information that they have on this at the EIS was not suitable for parents. End of story. In the meantime I had gone to the Medical Library and looked it up for myself.*[22]

3.33. Parents complained not only about the lack of information about their child's diagnosis, but also about not being informed of the possible condition of their child and the range of therapies for such conditions. A number of parents felt guilt and anger because they believed that if their child had received various therapies sooner, their child would be in a better condition today.

3.34. The Committee recognised that diagnosis can be a very long process, particularly with babies. It is also aware that a balance has to be found between informing parents of possible outcomes and not causing undue distress to parents with a more than likely normal child. The Committee also notes that it is a doctor's and not a therapist's role to make any diagnosis. However, the Committee was of the view that, at least in years gone by, professionals had erred on the side of not wanting to cause distress to parents.

3.35. The Committee also found that many parents were not able to access information about their child's condition or the range of services easily. Parents also noted that information needed to be provided at the appropriate time as information provided too soon would be forgotten as irrelevant. Information provided at a time of stress may be difficult to absorb and may require reinforcement. The Committee was informed that the provision of information had improved with the introduction of such things as the EIS providing a list of services available in the ACT. The Committee nevertheless brings to the Government's attention the need to provide appropriate accurate, timely, understandable and comprehensive information to its clients.

3.36. It was clear from the evidence given to the Committee that there was a desperate need for some kind of service coordination and information provision

22 Submission 8, p 1.

mechanism for families with developmentally delayed or disabled children. Parents required a person who would be a single point of contact whereby they could find out what kind of services were available for their child and plan a program that would take into account all of their child's and family's needs. Parents also needed someone who could assist in coordinating services when they encountered difficulties or crises. There was also a need for a coordination point in regard to each family from the side of the therapists and service providers so those providing a service could work in cooperation with other services rather than the child receiving different therapies and services in isolation. In short, a coordination point was required for each family so service could be integrated and holistic rather than isolated and piecemeal.

3.37. The Committee was also concerned that a child's ability to receive services depended largely on the parents' ability to advocate for it. As one parent put it:

Basically, they send you along to a therapy centre and say, "Look, go for it. Go and get yourself some therapy" and you basically gave to work it out from there. I think you have to be fairly assertive as a parent to get what you want. I think if you are not the sort of person that is prepared to say, "I want therapy once a month not" or "Once every two weeks" you can get it but, again, you are also talking to lots of other parents that also want the same thing and are not getting it and in some cases the parents are in a much worse sort of environment than you are and not getting what they really need because they do not know how to ask for it.[23]

3.38. This kind of view was not only expressed in relation to early intervention services but in relation to children's services in general.

The provision of services in the ACT seems now to us to be rather discriminatory against families who have not got the skills to go looking for the services that their children require. To actually find out where the services are and to access them in some cases is really quite a feat and if you are not educated and you are not articulate but you do want the best for your child that is not easy to do.[24]

3.39. The Committee considered that the most effective way to address these needs was for the Government to adopt a case management approach to providing early intervention services to families with a developmentally delayed or disabled child. The Committee considered that a case worker should be assigned to each family that will require coordinated early intervention services.

3.40. Who such a case manager should be would depend on the needs of the family. For a child with a single particular problem, such as speech

23 Uncorrected Proof Transcript, p 11.
24 Uncorrected Proof Transcript, p 150.

difficulties, it may be appropriate for the case worker to be the child's primary therapist. For a family that uses an Early Intervention Unit, a range of EIS therapies, special equipment and respite care, it may be appropriate for an EIS social worker to be the case manager. For a family with a child with a disability and behavioural problems it may be appropriate to have a specialised case manager. What is required is an accessible single point of contact for the family who can meet the coordination and advocacy needs of the individual family.

3.41. It is also recognised that not all families coming into contact with early intervention services would need a caseworker. Many children will only require a single therapy for a limited time. It would also not be appropriate to overwhelm a family by "case managing" it merely because it is considered that a child should be assessed when there is not yet any identified problem. It is therefore considered that case management need only be adopted when a child is diagnosed to have a moderate to severe or more than one disability or requires more than one type of therapy.

3.42. The Committee refers the Government to Victoria's Specialist Children's Services Family Service Co-ordinator as a case management model worthy of consideration.

3.43. The Committee recommends that the Government provide a case management service to families with a developmentally delayed or disabled child appropriate to the needs of the individual family.

3.44. It was evident that all early intervention services were operating under tight budgetary constraints and that demand for services outweighed supply. In regard to the CHADS EIS, it appeared that these constraints led the service to be run more in accord with administrative rather than client need. This is evident from, among other things, the statement from ACT Health that therapists on maternity leave are not replaced because of the tight health budget in the ACT.

3.45. In such a climate, it is essential that available funds are spent at the points of greatest need. It is also important that services respond to the needs of the client group, the families. To assist those outcomes, the Committee considers that, in combination with a case management approach, Government funding should be attached to the use of services by the clients.

3.46. To help ensure that services are provided where they are most needed, the Committee considers that a client purchasing model of service delivery should be adopted. Under such a model, the case worker and parents would agree to a program for appropriate services to be engaged to help reach agreed goals. The case worker would then purchase the agreed services on behalf of the client from the service provider, whether it be government or non-government.

3.47. This model would ensure effective parent input into the program for the child and ensure parental choice of services within appropriate guidelines. It would also establish a market for services where the services would be funded according to need for the service.

3.48. It would be necessary to establish an appeals process or dispute resolution mechanism to ensure that any disagreement between families and caseworkers about the appropriateness of and need for services could be resolved.

3.49. The Committee recommends that the ACT Government introduces a client purchasing model for early intervention services whereby services are purchased from service providers on behalf of the client according to a program agreed to by parents and their case worker.

3.50. The Committee is of the view that the above measures would enable early intervention services to be delivered more effectively. However, these efficiency gains will not solve all the problems in relation to the heavy case load of therapists.

3.51. The Committee is loathe to make recommendations in relation to increasing funding as it is aware of the budgetary restraints of the ACT Government and that it is not possible to put more money towards every worthy cause because to spend more money in one area means spending less somewhere else. However, the Committee considers that situations such as children missing out on essential therapy for months at a time because the Department cannot afford to replace a therapist on leave are intolerable.

3.52. The long term savings of money spent wisely on early intervention are apparent. It is inefficient to provide a therapy service which cannot maintain a consistent enough service to be properly effective. The Government also has a social obligation to provide adequately for those who are among the most vulnerable people in our community, the very young disabled.

3.53. It was also brought to the Committee's attention that families required more respite care than was currently available. A by-product of having family centred rather than institutionally centred services was that families needed opportunities to have time off from their role as carers.

3.54. The Committee recommends that the ACT Government increase its funding for early intervention services to a level where they can meet at least the basic therapy and respite care needs of their clients.

Parental Involvement

3.55. The Committee notes the importance of parental involvement in early intervention as parents are both the people with the prime responsibility for the

child and, in most cases, the child's primary care giver. Parents also have a special role as life long "case managers" and care providers.

3.56. The ACT Government's submission states that:

> *The ACT Government recognises that families are the significant people in the child's life as they bear the long term, ongoing responsibility for their child. Families are therefore seen as the decision makers regarding their child's program and take a key role in the child's assessment, programming and transition to future placements which will meet their child's individual needs. Choice of service remains the decision of each child's parents. The Government also acknowledges that the birth of a child with a disability may place the family in a very vulnerable and stressful situation. ...*
>
> *It is recognised that families also should be able, and encouraged, to participate in service development and evaluation of early intervention programs, both at the level of their own child's program and at a service level through surveys and client consultative groups.*[25]

3.57. The Committee found that, despite the Government's intention expressed above, often parents did not feel involved in the development of their child's program or the services at CHADS EIS. A number of parents gave evidence that they considered that their contributions had not been valued by EIS, their suggestions had been ignored and they were not involved in their child's program beyond being the passive recipient of directions.

> *...there should be a more open communication between therapists. We go in and we are told what we should be doing. We give suggestions and it is , "No, that is not going to work." We feel that we are not participating to the extent that we could be.*[26]
>
> *I felt as if I was not in control of the situation for a long time – as if all the therapists were having meetings and discussing our case and not telling us anything. This should be addressed – the family is the most important player in the team working for the child and should be treated accordingly. Once I got to the stage of feeling 'in control' I started looking around at alternatives and other resources available... At all times during this stage I was given the impression that if any alternatives were being tried not to mention it to the EIS because it would be looked down on, which puts extra stress on an already stressed family and makes decision making harder.*[27]

3.58. The involvement of parents in any program is not only important because of the parents rights and responsibilities in relation to the child but is also a crucial factor in having an effective program. As the primary care

25 Submission 16, p 6.
26 Uncorrected Proof Transcript, p 5.
27 Submission 8, p 2.

givers, the cooperation of and partnership with the parents is necessary to produce enduring outcomes from therapy sessions.

> *...there is certainly plenty of literature around which indicates that you should be addressing the perceived needs of the parents. If you are not doing that, then you are really not capitalising on that parent-child interaction and what is important for the parent and the child.*[28]
>
> *...an effective early intervention program has to actually take more account of family needs and the impact on the family of caring for these children, than it appears to be doing at the moment.*[29]

3.59. It is evident that the present structure of EIS does not provide sufficiently for client feedback. To address this problem, the Committee considers that parents should have the opportunity to be involved in the management of EIS to enable EIS to be more cognisant and sensitive to its client needs.

> *...it is an understandable, but totally erroneous approach to management in this disability area to assume that if parents do not complain, they are perfectly happy with the services. This approach does not even begin to understand how pressed for time parents in our position are. We do not have time to scratch ourselves, and simply cannot afford the time to phone and complain, let alone make an appointment and spend an afternoon voicing our concerns. Many parents cannot even get any respite care time, and if they could get some, they would spend it having a sleep, rather than complaining, which takes a further emotional toll.*
>
> *For these reasons, management is obliged to be pro-active in the welfare of the families which use its services, and provide some opportunity for the parents to provide feedback into the services.*[30]

3.60. The Committee is in favour of a board of management comprising parents, community experts and the Government being established for the EIS. To ensure that the composition, role and operation of such a board is suited to meet its objective of enabling all parents to have input into EIS's management, the Committee believes it would be necessary to have a parent based evaluation and consultation on the proposal. The Committee also considers that, due to the level of responsibility of the board and the sensitivity of issues and the variety of interests involved, decisions relating to the form of the board should be made by the relevant minister. The Committee believes that there ought not be a situation where a board is constituted such that Government representatives have a controlling vote.

28 Uncorrected Proof Transcript, p 87.
29 Uncorrected Proof Transcript, p 96.
30 Submission 4, p 3.

3.61. The Committee recommends that the Government conduct a parent based evaluation and consultation on establishing a parent, community experts and government representative board of management for Child Health and Development Services Early Intervention Services. The Committee also recommends that decisions about the constitution, role and responsibility of this board be determined by the appropriate minister.

4. USE OF CONDUCTIVE EDUCATION IN THE A.C.T.

What is Conductive Education

4.1. The National Health and Medical Research Council's (NHMRC) *Report on Conductive Education and Its Applicability in Australia* describes conductive education as "a system of education for children and adults with motor disorders originating from dysfunction of the central nervous system."[31]

4.2. Conductive Education was developed in Hungary by Dr Andras Peto, the founder of the now named Peto Institute.

> *Peto viewed motor disorders as learning difficulties to be overcome rather than conditions to be treated. He maintained that motor disorders should always be considered in relation to other aspects of development including cognitive, social, emotional, personality and academic learning. The education system Peto developed encourages people to learn how to help themselves overcome their disabilities. Peto thus provided an educational orientation to the rehabilitation of children and adults with motor disorders of neurological origin.*[32]

4.3. The Peto Institute offers a complex educational program through specialist teachers trained at the Institute called "conductors". The complete conductive education program to date is only provided in Hungary. However, programs using principles of conductive education have been established in countries in Britain, Europe and Asia and in New Zealand and around Australia. These programs are usually run by or use the services of a conductor trained at the Peto Institute.

4.4. The Canberra Centre for Conductive Education describes conductive education as:

> *a special teaching system which combines, in one integrated program, a range of exercises and educational activities. The program is designed to meet all the developmental needs - physical, social, emotional, cognitive and intellectual - of children with motor disorders.*
>
> *Conductive Education believes in the ability of children with disabilities to learn.*
>
> *Its aim is to help these children learn ways of achieving some degree of independence and mobility.*[33]

---

31 National Health and Medical Research Council, *Report on Conductive Education and Its Applicability in Australia*, 1993, p 1.

32 ibid, 1993, p 1.

33 Friends of the Brain Injured (ACT) Inc, Pamphlet on "Canberra Centre for Conductive Education".

History of Conductive Education in the A.C.T.

4.5. Conductive education began in the ACT when the Conductive Education Association of NSW provided the services of an Hungarian born and trained conductor, Ms Gabi Monus, to the Friends of the Brain Injured (FBI) to run a three month program from September 1990. Ms Monus stayed on in Canberra and the FBI took over her sponsorship, raising money through donations and students' fees. The Canberra Centre for Conductive Education was provided with accommodation by the Catholic Education Office, first in Kambah and later in Holder. The Centre had recently accepted an offer for alternative accommodation from the Department of Education and Training in Melba.

4.6. The Canberra Centre for Conductive Education continues to be run by FBI, a voluntary organisation run by parents. To date the Centre has not received government funding and has continued to be funded from fees and donations. This has required considerable effort from parents in fundraising activities.

4.7. The Centre has had over 40 children use its program and currently has 15 children. The current cost of the Centre is around $40,000 a year.

The Research Evidence for Conductive Education

4.8. Notwithstanding the universal belief in the efficacy of early intervention for developmentally delayed and disabled children, there is a scarcity of "hard" empirical evidence for the effectiveness of any particular program. This is in part due to the innate difficulty of obtaining such evidence. The NHMRC Report notes that:

> *Throughout the 1970s and 1980s, large numbers of early intervention programmes developed, many of which had a strong child orientation with a heavy emphasis on therapy or educational programming. Many attempts were made to prove the efficacy of these programmes in terms of developmental gains for the children. These attempts were often unsuccessful. In a review of research into the effects of intervention with children with disabilities Farran (1990) stated:*
>
> > *In general, studies that have used pre-post assessments on a single group show gains in the children's skills at the end of the program and achievement long term. These gains, however, are not always reflected in increased developmental quotients (indices that take mental age, chronological age, and the norm group into consideration), nor are they found in all areas of development. With no other children to which to compare the gains that were achieved, it is difficult to evaluate the success of these projects. There is no evidence that any particular programs were more successful than any others.*
>
> *In spite of this somewhat sobering conclusion, the majority of authors in this field have supported these programmes and point to variables such as the children's eagerness to learn, their overall happiness, the parent's satisfaction with the programme, and the quality of the parent's relationships with the child as indicators of the success of the programmes. The difficulty with these variables is that they have frequently not been formally measured, and indeed, this is often difficult.*[34]

4.9. In light of this, it is not surprising to find that there is no hard evidence for the superior effectiveness of conductive education. It is however apparent both from evidence given by parents and from various studies that conductive education has a very high rate of client satisfaction.

4.10. ***It does not appear to be at all under dispute whether conductive education is effective. What is under question is whether it is more effective than other early intervention programs or meets some otherwise unmet need to such a degree to warrant its further promotion and funding.***

4.11. The NHMRC Report cited a number of studies done on programs based on the principles of conductive education in Australia, all of which showed positive results. The report also cites a number of overseas studies, most of which had similar results. However, the report concluded that:

> *The few studies that have been undertaken outside of Hungary are generally characterised by flaws in their experimental design and most are descriptive, longitudinal studies; not controlled empirical studies....*
>
> *Cottam & Sutton's (1986) conclusion that "the claims made for Conductive Education have not yet been supported by "hard" scientific evidence" continues to be a fair and accurate statement.*[35]

4.12. What the NHMRC considered to be the most rigorous report to date, the "Bairstow Report", drew some sobering conclusions in relation to some claims for superiority of conductive education. The Bairstow Report compared the progress of children enrolled in the Birmingham Institute for Conductive Education with a matched subset of children enrolled in schools in Greater Manchester. The study concluded that:

> *While children receiving conductive education make progress on a wide range of functional and physical measures, there was no evidence to support predictions that they would achieve better rates of progress than children receiving alternative special education. On the contrary, the only evidence of differences in the rate of development was in favour of the group in Greater Manchester.*[36]

---

34 NHMRC, op cit, 1993, p 26.
35 NHMRC p 37.
36 "Evaluation of Conductive Education: Final Report", Bairstow et al, in NHMRC, op cit, p ix.

4.13. The Bairstow Report has been rigorously criticised, and it is evident that its findings are far from conclusive.[37] It is also the case that many of the criticisms of conductive education raised in the Report, such as it being highly selective of the children it will admit, do not apply to the programs practised in Australia.

The Experience of Parents

4.14. The NHMRC Report notes that:

> *It appears that the demand for Conductive Education in Australia is primarily consumer driven. Although some programmes have been initiated by professionals, the response from parents ensures that these programmes continue.*[38]

4.15. Conductive education is provided throughout Australia because parents are willing to invest significant amounts of time, energy and money to ensure it is available. This is no less true in the ACT where parents have maintained a conductive education program since September 1990 at the cost of some $40,000 a year without government support. However, the Committee notes the extra stress of annual fundraising puts on parents who already have to care for a child with a moderate to severe disability.

4.16. As one parent recounted to the Committee:

> *I was a bit sceptical about conductive education when I first went. I decided that during my school holidays I would take David along to a four week babies' and mothers' session and two weeks into that I was so impressed with what was happening and the different—the way I was seeing David so differently. Instead of a hand problem and a leg problem and a head problem and a vision problem and all these separate problems here was suddenly this little boy who was incredibly vulnerable and needed a great deal of support and, really, when I thought about it, well, look, I am his mother, I am the person who is obviously going to have to do that, so at that stage I decided that I was going to have to resign from my job, my full time job, and concentrate on giving David every opportunity to become as independent as possible.*
>
> *He is now doing some wonderful things. He is eating by himself sitting at a table, things that we just had no expectation that he would be able to do. His motivation has gone from non-existent—he would lie on the floor and if there was a rattle two inches away from him he would not even acknowledge it. He will now roll and grunt and groan and do everything he can to get where he wants to go. He is so motivated.*[39]

---

37 For a comprehensive critique of the report, see Prof A Russell, *Evaluation of Conductive Education, A Statistical Overkill: Challenging the Scientific Validity and Harsh Conditions of a University of Birmingham Trial*, 1994.

38 NHMRC, op cit, p 27.

39 Uncorrected Proof Transcript, p 80.

4.17. The support from parents for conductive education is due to both positive experiences with the program and dissatisfaction at other available services.

> *...a particularly important result for me personally is my daughter goes to both conductive education and Cranleigh. We pick her up from Cranleigh and she has been crying and we pick her up from conductive ed and she is laughing and that is the evaluation I look at.*[40]
>
> *I mean, on the question of how it works, my daughter had eight months of conventional therapy through the EIS. I left and went to conductive education and within a week her autistic-like expression had gone and she was smiling, she was laughing and she was animated. She was pretty verbal. Within three weeks she was standing up. Nobody had even tried to stand her up at EIS and we have that happen on a daily basis at conductive ed. We have people—parents coming in who cry for joy because for the first time in 18 months their child is sitting up at a table with other children.*[41]

The Applicability of Conductive Education Principles in the A.C.T.

4.18. The Committee found that the Canberra Centre for Conductive Education was providing a valuable service for children with motor disorders. The Centre provided an intensive, educationally based program for children with moderate to severe difficulties, it empowered parents to be involved in helping their child and gave them an understanding of their child's disability. The Centre helped some children achieve a number of goals which parents did not otherwise think their child would achieve, and parent satisfaction was sufficient enough for parents to make considerable personal sacrifices to enable their child to be in the program based on the principles of conductive education despite the availability of the free government provided services.

4.19. The Committee noted that there was not any evidence available isolating particular elements of conductive education as having a particular effect and was unable to determine whether any other equally intensive program would be more or less effective. It also noted the scarcity of evidence on the effectiveness of any program.

4.20. It noted that many of the elements of the conductive education program, such as approaches to giving parents an understanding of their child's disability and empowering families to help the child are worthy of adoption by any service.

4.21. The Committee endorsed the recommendation of the NHMRC calling for more research into all models of early intervention and noted that existing

---

40 Uncorrected Proof Transcript, p 41.

41 Uncorrected Proof Transcript, pp 41-42.

conductive education programs need to be maintained to enable their evaluation.

4.22. The Committee is aware that the NHMRC is funding a study by Dr Diana Reddihough into a "mothers and babies" conductive education program in Victoria which will compare the effectiveness of that program with conventional neurodevelopmental programs.

4.23. The Committee was of the view that given that:

- there was obviously a need for a service in the ACT in addition to those already provided by government services for children with a moderate to severe motor disability;
- the program based on the principles of conductive education was already meeting that need to the extent its resources would allow and was demonstrating positive results;
- services in general would benefit from a greater understanding and application of elements of conductive education; and
- there is an identified need for research into conductive education,

a program based on the principles of conductive education should be supported by the ACT Government and that program should be evaluated by an objective body capable of producing a study which would meet the standards of the scientific and medical community.

4.24. The Government should support this program in terms of both financial support and acknowledging it as an effective early intervention program. The Canberra Centre for Conductive Education is currently employing a full time conductor and has expressed the need for an additional preschool teacher.

4.25. The Committee notes that conductive education is an addition early intervention program, not an alternative to programs that already exist, and that financial support for conductive education should in no way adversely affect the Government's existing programs

4.26. The Committee recommends that the ACT Government provide funding for one conductor and one part time preschool teacher for a pilot program run on the principles of conductive education. This funding should not come out of funding for existing early intervention services.

4.27. The Committee recommends that the ACT Government commission a study of the pilot program by an objective body capable of producing a study which would meet the standards of the scientific and medical community.

4.28. Acknowledging programs based on the principles of conductive education requires acknowledging the role of the conductor. If the conductor is

to have a role as a specialised teacher for disabled children then it is necessary for the Government to provide for the registration of conductors. Such registration has been offered to conductors as teachers in Queensland.

4.29. The Committee recommends that the ACT Government provide for the registration of conductors as teachers in the ACT.

5. OTHER MATTERS THAT AROSE IN THE COURSE OF THE INQUIRY

Children at Risk

5.1. In the course of briefings given to the Committee, the issue of children at risk of harm from environmental factors such as neglect or abuse was raised. Dr Sue Packer, the Community Paediatrician, informed the Committee of the large number of children at risk who come to the attention of medical services in the ACT and the paucity of services available for such children, particularly the lack of family support services available.

5.2. Although CHADS EIS were used to help provide services for children at risk, the Committee considered that this issue lay outside the bounds of the current inquiry but was of too great an importance to ignore. In addition to the comments made at 3.11., ***the Committee wishes to raise the issue of services for children at risk as requiring the Government's attention***.

Vaccine Damage

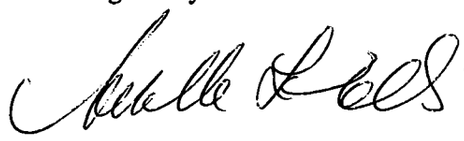
5.3. One of the submissions to the inquiry raised the issue of children who suffer from vaccine damage. The parents involved believed they had strong circumstantial evidence that their child's problems were related to a HIB vaccination.

5.4. The Committee in no way wishes to be involved in scare mongering in relation to children's vaccination and acknowledges that the benefits of vaccination far outweigh the risks. However, it considers that the concerns raised in the submission should be addressed.

5.5. The submission suggested improved information on the benefits and risks of vaccination, screening of children prior to vaccination, services for vaccine damaged children and reporting mechanisms. It also suggested a compensation scheme for vaccine damaged children similar to that in the USA.

5.6. The Committee was informed that an adverse reaction to vaccination is a notifiable event in NSW. It also understands that a no fault compensation scheme for vaccine damage exists in the USA because vaccination there is compulsory.

5.7. The Committee suggests that the issues related to vaccine damage be investigated by its successor in the next Assembly.



Annette Ellis
Chair
10 June 1994

APPENDIX 1: CONDUCT OF THE INQUIRY

The Committee received the reference from the Assembly to inquire into early intervention services on 21 October 1993.

The Committee advertised the inquiry in the *Canberra Times* on 13 November 1993 and 11 December 1993 and in the *Canberra Chronicle* on 16 November and 14 December; calling for submissions by 11 February 1994.

The Committee received 30 submissions, two of which the Committee decided to treat in confidence and one of which was subsequently withdrawn at the request of the author. The list of submissions can be found at Appendix 3. The Chief Minister's Department submitted a submission for the whole government. Supplements to three of the submissions were also received.

The Committee also received exhibits, which are listed at Appendix 4.

The Committee held a public hearing in the ACT Legislative Assembly on 25 May 1994. Evidence was received from parents; the ACT Government, represented by the Chief Minister's Department, Department of Health, Department of Education and Training, and the Housing and Community Service Bureau; community service providers and support groups. The Committee also took evidence *in camera* on 27 May 1994. The list of persons appearing at the public hearing is at Appendix 2. The Committee also received a private briefing form two paediatricians, Dr Sue Packer and Dr Angus McIntosh.

The Committee visited the Child Health and Development Service Early Intervention Service and met with members of its staff on 1 June 1994. Individual Committee Members also visited the Canberra Centre for Conductive Education. Mr Moore also held discussions with Prof Alan Charmichael, former Chair of the NHMRC Child Health Committee.

APPENDIX 2: LIST OF HEARINGS AND WITNESSES

25 May 1994

ACT Down Syndrome Association	Karen Connaughton
National Association for Conductive Education	Sue O'Reilly
Friends of the Brain Injured	Tony and Katrina Tucker
Parents	Kerry O'Kane and Keith Bradley Helen White Bob Greenfield Stephen and Sue Ferris Ross and Maria Carter Mahdi and Lloyd Chandler
Spastic Centre of NSW	Heather Brown
National Centre for Epidemiology and Population Health	Dr Jane Thompson
ACT Government	Rosemary Walsh, Barbara Ramsay (Chief Minister's Department) Heidi Ramsay, Jill Farrelly (ACT Health) Ken Horsham & Helen Briggs, (Housing & Community Services Bureau) Elsie Perkins (Department of Education & T raining)
Noah's Ark Canberra	Vicki McMinn Judith Roberts
QE II Hospital	Judy Jacobs Beverley Baker
Care for Kids in Crisis	Maisie Griffiths Kam Hardy Jan Marsh

27 May 1994 (in camera)

APPENDIX 3: LIST OF SUBMISSIONS

Person or Organisation

Brown, Heather
Spastic Centre of NSW

Carter, Ross and Maria

Chandler, Mahdi and Lloyd

Chief Minister's Department

Ferris, Stephen and Sue

Greenfield, Bob

Griffin, Bernadette

Griffiths, Maisie
Care for Kids Crisis

Hoskisson, Hazel
Tuggeranong Integration Team
Tuggeranong Community Service

In confidence

In confidence

Jacobs, Judy & Ms Beverley Baker
QE II Hospital

Jenkins, Pat

Kitchin, Jenny
Barnardo's Australia

Koh, Guan
Neonatal Intensive Care Unit
Woden Valley Hospital

McMinn, Vicki
Noah's Ark Canberra

McNamara, Gracie
The Canberra and Queanbeyan Attention Deficit Disorder Support Group

O'Kane, Kerry and Keith Bradley

O'Reilly, Sue
National Association for Conductive Education (ACT)

O'Reilly, Sue
National Association for Conductive Education (ACT)

Pellow, Denise
Royal Blind Society of NSW

Procter, Ann
CHADS Client Consultative Group

Scrivener, Lyn
ACT Down Syndrome Association

Strachan, Margot
Community Work Program
Tuggeranong Community Service

Stuparich, Jeremy
ACT Right to Life Association

Thompson, Jane
National Centre for Epidemiology and Population Health

Tucker, Tony and Katrina

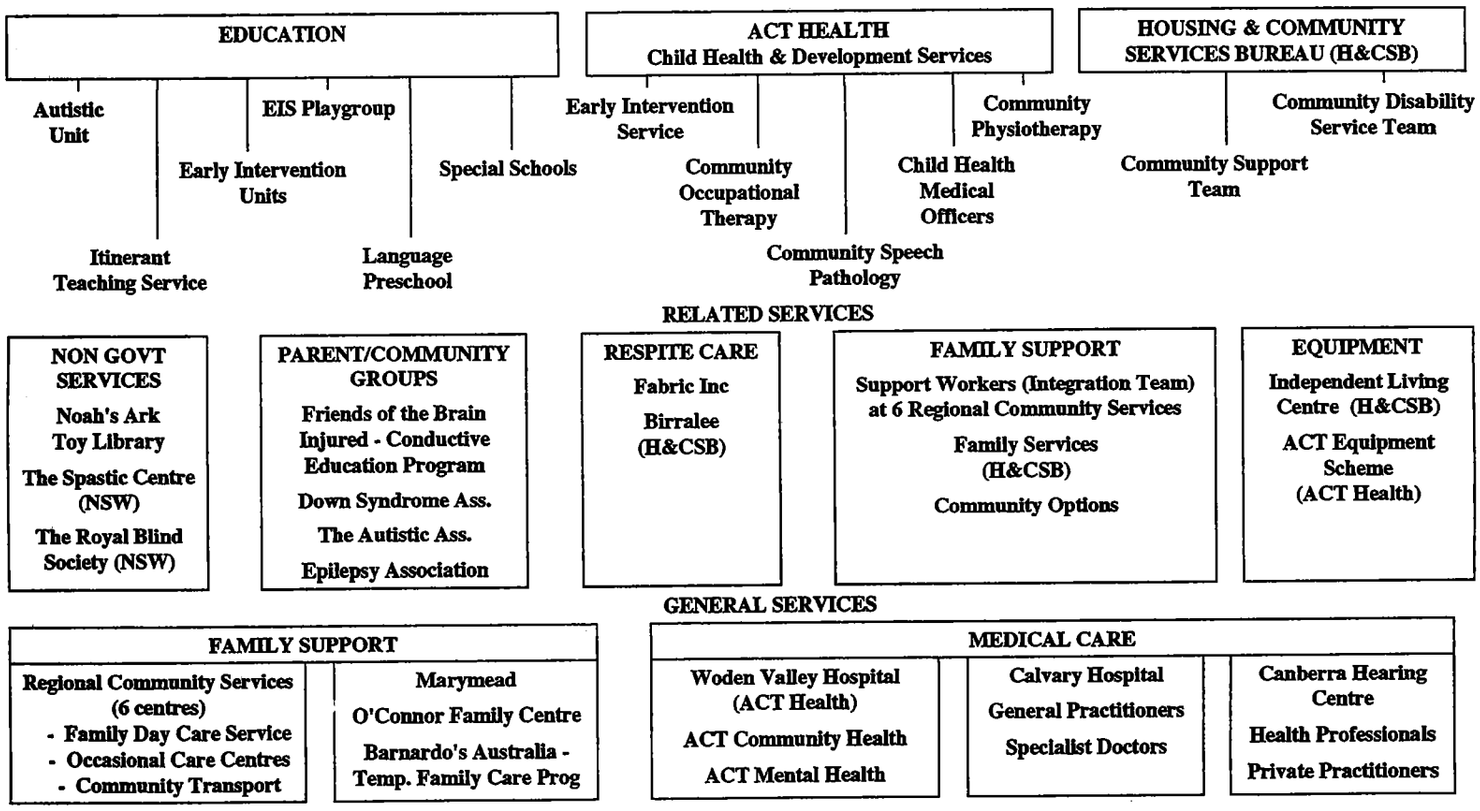
Tucker, Tony
Friends of the Brain Injured

White, Helen

APPENDIX 4: LIST OF EXHIBITS

Exhibit No.	Title/Document
1.	Letter from Ms Sue O'Reilly to Mrs Kate Carnell MLA, dated 18 January 1994
2.	Miscellaneous papers from the Child Health & Development Service regarding Early Intervention Services
3.	Media Release by Mrs Katrina Tucker, 27 May 1994

APPENDIX 5: EARLY INTERVENTION SERVICES IN THE A.C.T.[42]



42 Submission 16, p 13.

APPENDIX 6: A.C.T. HEALTH, SPECIALIST EARLY INTERVENTION SERVICES[43]

EARLY INTERVENTION SERVICE (EIS)	COMMUNITY SPEECH PATHOLOGY (SP)	COMMUNITY PHYSIOTHERAPY (PT)	COMMUNITY OCCUPAT.. THERAPY (OT)	CHILD HEALTH MEDICAL OFFICERS (CHMO)
- Age: birth to school entry - Prog Duration: 1 month -5yrs - needs based - No. clients: 461 - Location; Holder, outreach services at Turner, Melba - Waiting time: Nil - Multidisciplinary service; PT, OT, SP, SW, MO. - Eligibility: Children with, or at risk of, delays in development or disability - Range of individual, co-ordinated programs - Multidisciplinary & single discipline group programs - Consultancy available - Assessment -individual joint family/team designed programs - Home programs - Home visits available - Family team discussions - Review - Regular liaison with other services - Co location with < 3 yrs Early Education program - Client consultative Group	- Age: children of all ages - Prog Duration: 1 month - 3yrs - needs based - No. clients: 386 (0-5yrs) - Location: Health Centres, pre schools - Waiting time: 1-2 weeks for screening, up to 12 weeks for full assessment - Eligibility: Children with delays in speech /language, communication difficulties - Range of Speech Pathology programs: - Screening/advice/clinics - Assessment - Individual programs - Home programs - Group programs - Education programs - Outreach programs - Parent education programs - Language pre school - Consultancy to agencies - Close liaison with other services in case work - Co-ordinated programs with other services	- Age: children - adolescence - Prog Duration: 1 month - 2 yrs - needs based - No. clients: 229 - Location: Holder/ preschools /community programs - Waiting time: up to 4 weeks - Eligibility: Children with movement disorders/ delays in development/ postural problems/learning difficulties - Range of Physiotherapy programs: - Assessment-individual - Assessment-group - Individual programs - Group programs - Consultancy to agencies & child care centre staff - Outreach programs to preschools, incl Jervis Bay - Education training programs - Close liaison with other services in case work - Regular liaison with other services	- Age: pre / primary school - Prog Duration: 1 month - 2 years - needs based - No. clients: 193 - Location: Holder/pre schools /community programs - Waiting time: 5-6 months - Eligibility: Children needing assistance with hand skills, pre-writing skills and activities of daily living - Range of Occupational Therapy programs: - Screening program - Assessment - Individual programs - Group programs - Outreach programs to pre schools - Consultancy to pre schools - Education training programs - close liaison with other services in case work - Regular liaison with other programs	- Age: birth-adolescence - Prog Duration: Mostly single visits, some review - Location: Holder, Turner and Community Health Centres - Waiting time: Urgent cases immediately-others 1-4 wks - Eligibility: All children - Medical assessments - Developmental assessments - Consultancy to parents, professionals, community organisations - Referrals to CHADS and other services - Medical referrals - Liaison with CHADS staff - Liaison with specialist doctors and GPs - Liaison with baby health clinics, day care centres - Regular liaison with other services re case work - Regular liaison with other programs

43 Submission 16, p 17.

APPENDIX 7: DEPARTMENT OF EDUCATION AND TRAINING EARLY INTERVENTION PROGRAMS[44]

EARLY INTERVENTION SERVICE PLAYGROUP	EARLY INTERVENTION UNITS	SPECIAL SCHOOLS	AUTISTIC UNIT	ITINERANT TEACHING SERVICE
- Age: 18 months -3 years - Prog Duration:< 12 mths - *No. students: 72. 1x FTE teacher +1.5 FTE aides Dept Ed, + 1.5 x FTE teachers are DEET funded - Location: Holder - Waiting time: 6 months - Eligibility: children with, or at risk of, delayed development or disability - Early childhood education program in a small class - Daily liaison with EIS team - Home Programs - Home visits when necessary - Pre school counsellor service - Regular liaison with other services *DEET funded .5 FTE teacher works together with the Playgroup teacher with 49 of the 72 children *An early childhood educator provides a home based program for 23 children aged 9 months -2 years. This is a DEET funded program.	- Age: 3 - 5 yrs - Prog Duration: <12 mnths Continuity is needs based - No. students: 120 - Giralang, Turner, Rivett, Monash, Fadden - Waiting time: Nil - Eligibility: As for EIS Playgroup - Early intervention education program - Small class of up to 12 children with parent participation - Home programs - Home visits if necessary - Consultation to children's programs from CHADS Early Intervention Service - Liaison with Community Services SUPs workers - Pre school counsellor service - Liaison with pre school resource teacher	Malkara - Hughes Age: from 3 yrs. Students: 23 Cranleigh - Holt Age: from 3 yrs. Students; 26 Turner Early Childhood Program: Turner/Richardson Age: from 3 yrs. Students: 33 Prog Duration: Needs based - annual review of placement - Eligibility: As for EIS PG - Waiting time: Nil - Early Intervention Education Program - Small class, 8-10 students with teacher and aide - Integration sessions in mainstream pre schools encouraged - Consultation from EIS to Turner School - Consultation from Community Disability Services re individual children's programs at Malkara & Cranleigh - Home visits -Cranleigh, - Malkara - Liaison with pre school resource teacher - Regular liaison with other programs	- Age: 3 to 8 yrs - Prog Duration: Needs based - annual review - No. students: 8 - Location: Hughes - Waiting Time: Nil - Eligibility: Diagnosis of Autism - Special structured education program- - Transitional program & appropriate integration - Support provided for integration in mainstream - Input to children's programs from CHADS LANGUAGE PRE SCHOOL - Age: 3 to 5 yrs - Prog Duration: Needs based - annual review - No. students: 22 - Location: Griffith - Waiting time: Up to 10 wks - Eligibility: Special education & SP assessment(CHADS) - Joint education / SP special program for speech/language delay - Pre school counsellor service - Liaison with pre school Resource Teacher - *Salaries for this program are DEET funded	**Hearing Impaired Children** - Age: From diagnosis - Prog Duration: Needs based - annual review - No. children: 24 - Eligibility: Appropriate AHS audiogram - Waiting time: Nil - Regular home visits - Integration programs - Support in pre school class - Consultations provided - Liaison with pre school resource teacher - Liaison with Canberra Hearing Service and SP **Vision Impaired Children** - Age: From diagnosis - Prog duration: Needs based - annual review - Eligibility: Appropriate ophthalmological report - No. children: 6 - Waiting time : Nil - Regular home visits - Support in pre school class - Consultations provided - Integration program - Liaison with pre school resource teacher - Liaison with Royal Blind Society(NSW), Guide Dog Ass., Canberra Blind Society

44 Submission 16, p 14.

APPENDIX 8: HOUSING & COMMUNITY SERVICE BUREAU EARLY INTERVENTION SERVICES[45]

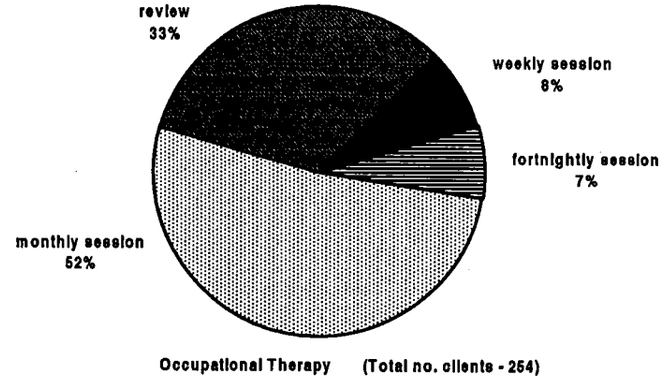
COMMUNITY DISABILITY SERVICES	COMMUNITY SUPPORT TEAM - RESPITE CARE
- Age: from 2 yrs onwards - Prog Duration: Needs based - No. clients: 79 (EI clients) - Location: Homes, Malkara/ Cranleigh Schls, Day Care - Waiting time: Varies -with recruitment, current OT list of 3. PT/SP currently nil - Multidisciplinary resource team; PT, OT, SP, SW PSYCH - Eligibility: Children with significant delays in development - Programs: Vary according to client needs - Individual programs - Case Management - Consultancy - Close liaison with Community Support Team Recreation and Respite Care and with the Independent Living Centre - Regular liaison with special school staff - Liaison with Family Services	- Age Group: 1 - 16 yrs - Prog Duration; 7 days per month - No. clients: 8 > 5 yrs age (Total of 81 clients) - Location: Birralee Hostel Melba - Waiting Time: 4 children > 5 yrs currently waiting - Eligibility: Intellectual disability or Developmental Delay - Centre based care - Planned and emergency respite care - Close liaison with Community Disability Services and Recreation - Liaison with Special Schools - Liaison with Fabric, ADACAS, Day Care Centres, Community Centres - Liaison with Family Services

45 Submission 16, p 20.

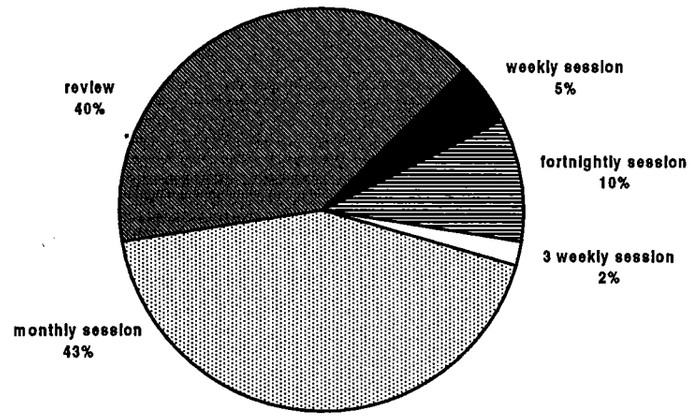
APPENDIX 9: CHILD HEALTH & DEVELOPMENT SERVICE THERAPY FREQUENCY[46]

Figure 2: Frequency of Therapy Sessions at ACT Health Early Intervention Service

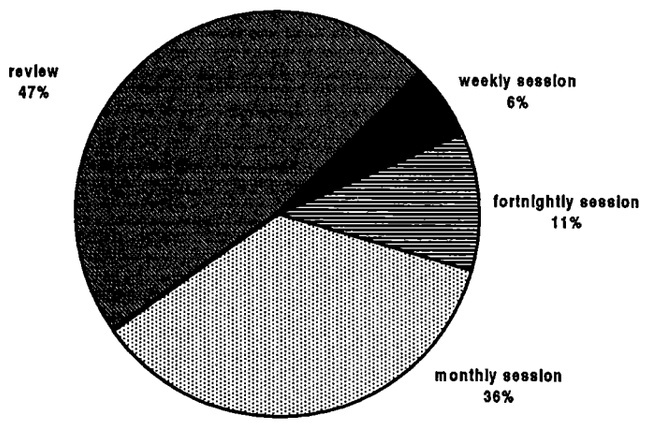
Figure 2 illustrates the frequency of sessions accessed by children in November 1993. A session is usually up to an hour long. Therapy programs are often on a long term basis. The individual therapy components as illustrated reflect the patterns of sessions and are those actually accessed in November 1993. EIS looks at the needs of the whole child and responds to current needs. For example a child may be on weekly physiotherapy with a detailed home program for a 6 week period to gain a specific objective. During this time speech pathology may be provided in a monthly program and the occupational therapy program may be on long term review basis.



46 Submission 16, ch 7.



Physiotherapy (Total no. of clients - 314)

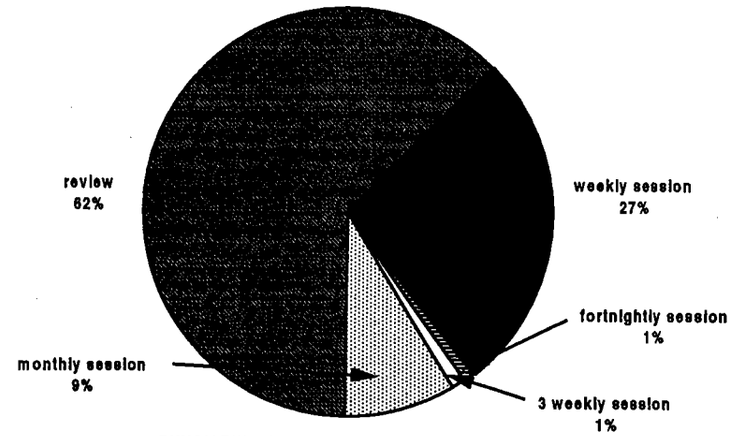


Speech Pathology (Total No. of clients - 255)

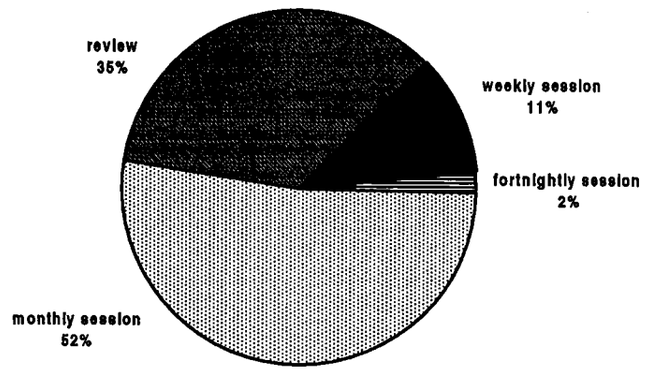
Note: In the Early Intervention Service 177 client families have been contacted by social workers. Child Health Medical Officers have seen 314 of the children.

Figure 3: Frequency of sessions in ACT Health (CHADS) Community Services

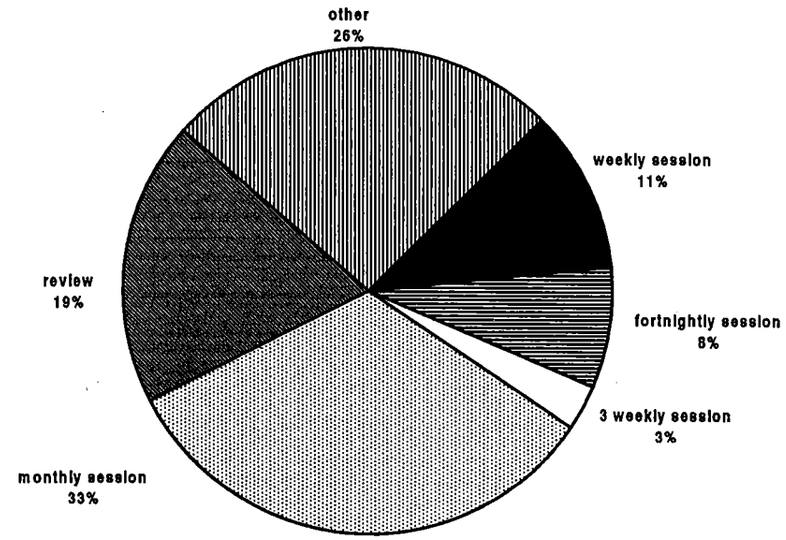
Figure 3 illustrates the frequency of sessions accessed by children in November 1993. Children seen by Community Services generally tend to be seen on a shorter term basis than in EIS and are only occasionally seen for extended, regular therapy. Some families request to attend a community service. They may have short, intensive bursts of weekly individual therapy or group programs and then be placed on review or discharged.



PHYSIOTHERAPY (Total No. of clients - 228)



OCCUPATIONAL THERAPY (Total No.of clients - 221)



SPEECH PATHOLOGY Inc. Language Preschool (Total No. of Clients - 389)