

Advice to the Minister for Families, Housing, Community Services and Indigenous Affairs / Parliamentary Secretary for Disabilities and Children's Services

# Policy on Early Intervention for Deaf and Hard of Hearing Children

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# 1. Introduction

# 1.1 Background

Early intervention in the context of this policy paper is defined as intervention programs that occur during the period from birth to school age.

Early Intervention for children who are deaf or hard of hearing is a vital but vexed issue. It is vital that these children are able to acquire a language to native fluency within the early language learning years and that their families are able to communicate effectively with them. (Most deaf children are born to hearing families who are not able to use sign language, the natural language of the Deaf Community.) It is also vital that from the beginning these children are enabled to develop a positive self image and be confident about themselves and their place in the world. Unfortunately the advice given to parents is often inaccurate and inadequate, and Early Intervention services available to them are also often inappropriate and inadequate.

Over the past few years, Universal Newborn Hearing Screening programs have been rolled out nationally. Because the majority of deaf children are now being identified soon after birth, Early Intervention has become a much more pressing issue than it was in the past. Historically Australia has not been providing a lot of Early Intervention to deaf children, particularly before the age of three, as until recently few of them were identified very early.

A large percentage of early identified deaf children are now receiving cochlear implants (close to 100% in some places). While this device can give children early access to sound (including the sounds of language), it can also create the expectation that they are 'cured' and will need less in the way of support as they grow up. This expectation is unrealistic. Anecdotal information from educators indicates that children with cochlear implants in schools sometimes require more support services than those without them. Parents need to be given more extensive information to help them manage expectations and make fully informed decisions.

Early Intervention services vary nationally. Some states have better services than others.

The education of deaf and hard of hearing children has always been characterised by differences of opinion and method, so the wide range of approaches described in this paper are at least partly the result of this history, not necessarily because Australia has been unusually inconsistent or haphazard in developing these services.

Clear, comprehensive and easy to understand information about Early Intervention services is not easy to find. Comments from parents for this paper highlighted the issue of the rights of parents to make informed choices about their child's future. It is the right of the parents to choose for their child but professionals must make information available about the choices – whether or not all of the choices are locally available.

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Deaf Australia strongly supports and advocates for Early Intervention services that aim to enable the child to acquire equal skill in both a spoken language (English) and a signed language (Auslan), and for the family to acquire Auslan.

However, few Early Intervention services provide this. Most advice given to parents leads them to believe that they must choose between signing and speech and that speech is the better option. This is related to a medical focus on fixing/curing the hearing loss. Most Early Intervention programs provide access to spoken language only and it is believed that the majority of deaf and hard of hearing children are enrolled in these monolingual programs. Deaf Australia believes this approach is inappropriate, inadequate and potentially damaging to the child, and does not promote healthy family relationships.

The United Nations Convention on the Rights of Persons with Disabilities clearly states:

#### Article 24 - Education

- 3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:
  - a. Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;
  - b. Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;
  - c. Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.
- 4. In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.

Deaf Australia has developed a Vision 2020 statement which sets out what we believe deaf people's lives should look like by the year 2020. It is based on the World Federation of the Deaf Vision 2020, which in turn is based on the UN CRPD. In relation to Early Intervention, it states:

Auslan is respected and accepted as part of the diversity of the Australian community. Auslan in education, provision of services, social interactions and participation in society is taken for granted and guaranteed by legislation. Everybody has the opportunity for natural linguistic development, high quality education and life-long learning.

Research and documentation of Auslan has significantly advanced, and legislation of the rights of people to use Auslan as their native language has been implemented.

#### Deaf Education is of a High Quality

All deaf education is bi-lingual (Auslan/English) or multi-lingual (Auslan/English/other); and education for Deaf children and Deaf adults is equally important.

#### **Families**

Programs are provided for families of Deaf children to ensure the home environment fosters and protects the needs of the Deaf child as regards communication, development and family interaction.

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Deaf Australia would like to work with the Australian Government on making this vision a reality.

In this paper Deaf Australia provides an introduction to the issues that need to be more thoroughly examined for the Australian situation, and proposes a way forward for Early Intervention for children who are deaf or hard of hearing.

# 1.2 Purpose

Deaf Australia has long been concerned about the issue of Early Intervention for children who are deaf or hard of hearing and wishes to be proactive in working to improve the situation. In the context of the Australian Government's commitment to social inclusion we would like to see Australia implement a national system of best practice Early Intervention programs for children who are deaf or hard of hearing.

In addition, on 31 July 2008 Deaf Australia met with the Parliamentary Secretary, Bill Shorten, and Early Intervention was discussed during this meeting. The Parliamentary Secretary asked Deaf Australia to prepare for him a proposal for action.

# 1.3 National Relevance

Currently the Early Intervention options a family is able to access depend very much on where they live and in many areas there are very few if any options available locally.

There is no national standard for Early Intervention for deaf and hard of hearing children and no coordination of services. Deaf Australia contends that there ought to be. Early Intervention programs set the child up for life and have an on-going and long term impact on life choices and service needs.

At the very least there needs to be agreement between the State, Territory and Australian Governments on provision of and standards for Early Intervention services. Early Intervention services also need to be specifically identified for funding programs at either the national or State/Territory level (or both) within an agreed framework. The question of what age range Early Intervention relates to and who is responsible – health, education or disability portfolios – also needs to be resolved nationally.

# 1.4 Relevance to FaHCSIA Portfolio

FaHCSIA's portfolio includes services and assistance to families to promote healthy family relationships, including early intervention programs, and also services for people with disabilities.

# 2. Issues & Impacts

# 2.1 Issues

# A. What early intervention services are currently available?

There are two main sources of information that were used for this policy document – the Aussie Deaf Kids website at <a href="www.aussiedeafkids.org.au/early-intervention-services.html">www.aussiedeafkids.org.au/early-intervention-services.html</a> and the Choices booklets published by Australian Hearing and available on their website at <a href="www.hearing.com.au/fact-sheets">www.hearing.com.au/fact-sheets</a> These are not the only sources available or the only way to find information about Early Intervention services. We chose these sources because our time and resources for this investigation were limited so we needed to use sources that gave a reasonably comprehensive overview of what is available. The Choices booklets are given to most if not all parents of newly diagnosed deaf and hard of hearing children, and it is our understanding that the Aussie Deaf Kids website is widely accessed by parents.

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The way in which different Early Intervention service providers describe their programs is not always clear and consistent. Generally speaking, it is claimed that there are three types of Early Intervention programs: oral-aural / auditory-oral, including auditory-verbal; total communication; and bilingual. Australian Hearing's *Choices* booklets describe these three methods as follows.

#### AUDITORY-VERBAL/ ORAL-AURAL

Programs using the auditory-verbal or oral-aural approach focus on the use of even minimal amounts of amplified hearing to develop spontaneous speech and to process language in a natural way through auditory pathways. These programs enable children with hearing impairment to learn to listen, understand spoken language and communicate through speech using their residual hearing, and in the oral-aural approach, using lipreading as well. These programs usually place the parent in the role of primary educator.

#### TOTAL COMMUNICATION

Programs supporting a total communication philosophy focus on the use of a wide range of methods of communication including speech, lipreading, listening, signing and finger spelling. These various methods of communication may be used alone or in combination with each other. When speech and signing are used together this is known as simultaneous communication. Simultaneous communication is used to manually represent English using a sign system known as signed English.

#### BILINGUAL/BICULTURAL

Programs supporting a bilingual/bicultural approach focus on education through two languages, Auslan and English. English is taught as a second language via reading or writing or through sign systems representing English. In many educational programs and school settings, children who are Deaf or hearing-impaired may learn about the Deaf community and its history, language and culture, as well as learning about the hearing community.

Not everyone would agree that these are the most accurate descriptions. For example:

Auditory-verbal programs: "....enable children with hearing impairment to learn to listen...." In Deaf Australia's view it is more accurate to say "...aim to enable..." To say that they "enable" is misleading.

Total communication programs: Deaf Australia's view is that these programs in practice are more properly described as simultaneous communication using speech and signed English.

Bilingual/bicultural programs: These programs now are usually referred to as bilingual. As well as English taught as a second language via reading or writing, bilingual programs also include oral-aural elements. Bilingual programs should present the two languages as separate languages. For these programs, this paper uses the term 'bilingual'.

However, the descriptions above, taken from the *Choices* booklets, are the descriptions that almost all Australian parents new to information about deafness are initially given.

The Aussie Deaf Kids website provides more comprehensive descriptions of these options, and Deaf Australia sees some inaccuracies and inadequacies in these descriptions also.

Although it is not separately described in the *Choices* booklets, the information about programs available on these two websites also identifies a fourth option, Auslan – and many websites of individual organisations also identify Auslan as a communication option – but do not describe what this means in terms of how it is delivered in Early Intervention programs.

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## Understanding what the options mean

Different organisations often describe their programs differently and a fundamental confusion that is perpetuated in descriptions of and discussions about Early Intervention programs is that many different terms are used – options may be described as a therapy, a communication method, a philosophy, or a pedagogical method. Everything also tends to be described at some point or another as a communication option. This confusion of terms can be misleading and adds to the confusion for families and may result in decisions being based on inaccurate and insufficient information about what is actually going to happen in different programs.

In an attempt to be clear about what is being discussed in this paper, the different options are identified as "approaches" and Deaf Australia's understanding of the different approaches is summarised as follows.

The **Auditory-verbal** approach focuses on the development of listening skills and speech. These programs do not allow the use of visual communication skills such as lipreading or signing. Auditory-verbal programs aim to enable the child to learn to use their residual hearing with cochlear implants or hearing aids to speak and interact with the hearing community. Auditory-verbal programs are not necessarily provided by a trained teacher of the deaf; they are frequently provided by speech therapists. A good source of information about the principles of auditory-verbal approach can be found on the Hear and Say Centre website <a href="https://www.hearandsaycentre.com.au/principles-AVT.html">www.hearandsaycentre.com.au/principles-AVT.html</a>

The **Auditory-oral / oral- aural** (for the purpose of this paper we will use **oral-aural**) approach also focus on the development of speech and listening skills, with the aim of developing speech skills to enable interaction with the hearing community. They allow the use of some visual communication skills, i.e., lipreading.

Auditory-verbal and oral-aural programs focus to some extent on English language development but this is not the key priority, the priority is listening and speech development. It is important to understand that speech and language are not the same thing. A person can have good speech but poor language fluency, and vice versa – and this is true of many deaf people.

The **Total communication** approach is based on the idea that all communication skills and methods (speech, lipreading, listening, signing and finger spelling) are offered and whatever methods work best for a child are used with that child. However, in practice it has almost always come to mean that speech and signing are used together with all children in the program – a practice that is more properly known as simultaneous communication but has come to mean total communication in many if not most Australian Early Intervention and education programs.

The signing used in total communication programs is usually an artificial sign system called Signed English. It is not possible to sign in Auslan and speak in English at the same time because the two languages and their structures are different. (People who observe Auslan users signing and speaking at the same time often get confused about this point. It is important to understand that when Auslan users speak at the same time as they sign, they are not using Auslan as it is used among Deaf people themselves, they are modifying it to suit the situation and the audience. Please see the attached information sheet for more information about Auslan and other forms of signing.)

The **Bilingual** approach uses both Auslan and English to communicate with the child. The focus is on language development and the whole child. Bilingual Early Intervention programs incorporate therapy such as speech and listening. These programs aim to enable the child to acquire two languages (English and Auslan) equally or at least one language (usually Auslan) to native fluency and the other (usually English) as a second language and to interact competently and confidently in both hearing (English) and Deaf (Auslan) communities. Bilingual programs should present both languages as two separate language models.

It is not possible to reliably predict a deaf or hard of hearing child's language preferences or speech abilities, and degree of hearing loss is not always a reliable indicator of eventual outcomes. Some

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children are able to acquire both languages to an equal level of competence; others may be more dominant in one language and use the second language as a support, especially when learning new concepts. Once children have mastered a first language, acquiring a second language becomes much easier. For the developing brain, it makes no difference which particular language code (speech or sign) is processed as long as at least *one* language is taken up as the native language within the critical period of development, birth to age six but preferably birth to age three.

Exposing a very young deaf child to both a spoken and a signed language during these critical early language learning years provides a safety net for acquisition of at least one strong language for future learning. If a child's first language can be acquired within normal developmental milestones there is a much greater chance that they will be able to use their language skills to achieve to their best potential and have a wider range of educational and vocational opportunities. In a monolingual or oral-aural approach valuable time can be lost waiting for speech to emerge and the critical period for language acquisition can be compromised, resulting in delays in language and general learning skills.

Not enough is known about how very young children use their residual hearing and how information is processed. So bilingual Early Intervention approaches enable the child to develop both a signed language and a spoken language and allow the child themselves to naturally choose which language (or both more or less equally) they prefer.

**Auslan** is the sign language of the Australian Deaf community. It has evolved from the sign languages brought to Australia during the nineteenth century from Britain and Ireland. Its grammar and vocabulary are different from English. It is a natural language that has developed over time. Auslan was recognised by the Australian government as a "community language other than English" and the preferred language of the Deaf community in national policy statements in 1987 and 1991. Even though Auslan has been proclaimed a Community Language, it is still a minority language, and it is important for this to be taken into account when planning early intervention programs.

When organisations say they offer an Auslan approach it is not always clear what this means. It is rare for Auslan to exist in an Auslan-only environment; even in families where everyone is deaf and fluent in Auslan there is exposure to English in some form. However, offering Auslan as an option does not automatically mean that the approach is bilingual. (It is also true that when an organisation says it offers a bilingual approach the program may not be 'truly' bilingual, it may focus on Auslan with English as the poor cousin.)

It may be that 'Auslan approaches' offer Auslan in the context of a longer term bilingual approach, with an early focus on the development of Auslan as a first language. The program may not yet be formally teaching English (though they will usually provide exposure to many aspects of it – sight words, fingerspelling etc). Some Early Intervention programs that describe themselves as Auslan approaches are known to be connected to a bilingual school-level program and there may be a plan for the Early Intervention stage to focus mostly on Auslan, with English being introduced at preschool level (e.g. in Brisbane the Yeerongpilly Early Intervention program is a feeder program to the bilingual school program at Toowong State School; in Sydney the RIDBC Roberta Reid Centre is an Early Intervention program whose children often then attend RIDBC's Thomas Pattison School – although there are some questions about how bilingual Thomas Pattison's program actually is, it is possible it may be Auslan focussed more than it is bilingual).

Early Intervention providers that say they offer Auslan programs are mostly State Departments of Education (but also RIDBC – NSW, and statewide through their Teleschool, and CanDo4Kids – SA).

In addition, a common problem with Auslan programs is that it is not clear how fluent in Auslan are the staff delivering the programs. It is Deaf Australia's experience that very few teachers of the deaf have a high level of fluency in Auslan. It is not sufficient to just know some signs; fluency is vital. In particular, a notorious weakness among hearing people who work in Auslan/English bilingual situations (Early Intervention, schools, interpreting) is the skill variously referred to as "reading back", "reverse interpreting" or "Auslan/English translation/interpreting" – i.e., the ability to read

Auslan and translate it into English. Auslan Early Intervention programs do not state what competency levels their staff have.

# **Organisations providing Early Intervention Programs**

To develop an overall picture of who is providing Early Intervention programs and what type of programs they are providing, we cross referenced information from the Aussie Deaf Kids website and the *Choices* booklets as at end February 2009. This resulted in the following information about currently available services provided by key organisations.

Table 1: Organisations providing Early Intervention program and types of programs they

provide

State   Early Intervention program   Program types offered												
State	Early Intervention program provider	Program t	types offer	ed								
		Auditory- verbal	Oral- aural	Total communication	Auslan	Bilingual - Auslan/ English	Other					
ACT	ACT Department of Education, Youth and Family Services	<b>√</b>		$\checkmark$		<b>V</b>						
NSW	Department of Education and Training - Disability Programs		V	<b>√</b>	<b>V</b>							
	Royal Institute for Deaf and Blind Children (RIDBC) (not all options are offered at all locations)	<b>√</b>	<b>√</b>	V	<b>√</b>							
	St Gabriel's ("Hear the Children")	<b>√</b>										
	The Shepherd Centre	√										
	St Dominic's Centre for Hearing Impaired Children		V									
	Catholic Centre for Hearing- Impaired Children		V	$\checkmark$			cued speech					
NT	Department of Education and Training	Services provided are determined by the needs of the child and availability of resources.										
QLD	Hear and Say Centre	<b>√</b>										
	Taigum Early Childhood Development Program (Education Queensland)	V	<b>√</b>		V							
	Yeerongpilly Early Childhood Development Program (Education Queensland)		<b>√</b>		V	<b>√</b>						
SA	Early Intervention Service - Hearing Impaired, Department of Education and Children's Service	V			V		signed English					
	Cora Barclay Centre	√										
	CanDo4Kids	√	√		√							
	Kilparrin Teaching and Assessment			$\checkmark$								
TAS	Services for Deaf and Hearing Impaired Students, Department of Education		V		V							
VIC	Parent Advisor Service for Families of Hearing Impaired Children, Department of Human Services – Specialist Children Services	V	<b>√</b>	<b>V</b>	√							
	Taralye	√	√									
	Aurora School					<b>V</b>						

Submission 46 - Attachment 1

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	The Early Intervention Program for Hearing Impaired Children	\ \	<b>√</b>		visual communication
WA	WA Institute for Deaf Education (WAIDE)		1	V	
	Telethon Speech & Hearing Centre	<b>√</b>			
Multi- state	RIDBC Teleschool (all states and NT)	V	<b>V</b>	V	
	Hear and Say Centre - Outreach (NT, QLD)	<b>V</b>			
	The Shepherd Centre (NSW, ACT)	<b>√</b>			

In preparing this paper we asked for feedback from our panel of education experts and others, including some people associated with some programs, and we checked the websites of key organisations. While the information on websites generally matched the information in table 1, the information we were given informally was in some cases different. For example, we were informally advised that:

- CanDo4Kids in SA has a bilingual program but their website does not say this.
- 2. WAIDE in WA until recently provided two separate programs: oral-aural and Auslan; they have this year changed this to a bilingual program.
- 3. It is doubtful that NSW Department of Education and Training provides Auslan programs.
- 4. Parent Advisor Service in Victoria does not provide Auslan programs. It also is unlikely to be providing total communication programs.
- 5. The information about the Parent Advisor Service in Victoria is misleading information on the Aussie Deaf Kids website indicates services are provided in 6 locations but informal advice indicates it currently is provided only in one location.
- 6. Some oral-aural programs (e.g. Taralye) allow some signing but this is not encouraged or advertised even though it is contrary to the school's philosophy some teachers will be flexible in practice if there is a perception a child needs signing. It is not clear what kind of signing is used.
- 7. Queensland has two additional Early Intervention programs at Townsville and Ipswich.
- 8. Services are also provided by hospitals and programs attached to the Universal Newborn Hearing Screening programs that have been rolled out over the past few years but it is not clear what these services are.

Information in this paper therefore was at February 2009 approximately indicative of the situation in Australia, but a detailed and more extensive investigation needs to be undertaken and discerning questions need to be asked.

To summarise the information in Table 1:

- 1. Twenty-two organisations provide Early Intervention programs.
- 2. Three of these organisations also provide outreach programs to other states.
- 3. Some of these organisations provide only one type of program:

Table 2: Organisations providing only one type of program

Auditory-verbal	St Gabriel's ("Hear the Children") – NSW
	The Shepherd Centre – NSW
	Hear and Say Centre – QLD
	Cora Barclay Centre – SA
	Telethon Speech and Hearing Centre – WA
Auditory-oral / Oral-aural	St Dominic's – NSW
Total Communication	Kilparrin Teaching and Assessment – SA
Bilingual	Aurora School – VIC

- 4. The remainder provide a number of different options.
- 5. In total, the following types of programs are provided by these organisations.

Table 3: Total number of programs provided, by type of program.

Program types offered												
Auditory-verbal / Oral-aural	Total communication	Auslan	Bilingual - Auslan/ English	Other								
29	6	10	3	3								

6. Information about Early Intervention services specifically for Indigenous deaf and hard of hearing children is not readily available.

# Locations of service provision

Four organisations provide Early Intervention programs in multiple locations:

RIDBC (Auditory-verbal, Oral-aural, Total communication, Auslan) The Shepherd Centre (Auditory-verbal) Hear and Say Centre (Auditory-verbal) Aurora School (Bilingual)

St Gabriel's (Auditory-verbal) also seems to provide services in more than one location but it is not clear where or how many.

In all States and Territories, Departments of Education say they provide services statewide; however, it can be very difficult to find specific information about specific services and where they are located. Most provide only minimal, if any, clearly identified Early Intervention programs for children younger than three years: State Departments of Education tend to define Early Intervention as being outside the scope of their "client base"; most do not seem to see their responsibilities beginning until the child is aged three. According to the information available on the Aussie Deaf Kids website and the *Choices* booklets, Catholic education services also do not seem to see Early Intervention as being part of their brief, with NSW being the exception.

The table below shows information about identified locations of Early Intervention programs.

**Table 4: Number of program locations** 

Number of program locations*	#	%^
NSW	18	34.61
VIC	10	19.23
QLD	9	17.3
SA	5	9.61
WA	3	5.76
NT	3	5.76
TAS	2	3.84
ACT	2	3.84
Total	52	99.95

<sup>\*</sup> Includes only program locations that can be identified from information easily accessible. Most state Education Department programs are counted only as one 'statewide' location, as are outreach programs in each state as information is not readily available on specific locations.

For each program location, information from the Aussie Deaf Kids website and the *Choices* booklets at February 2009 was compiled about the program options offered.

Table 5: Programs offered in each location

	AC	ACT NSW		N	NT		QLD		SA		TAS		VIC		WA		National	
	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%
Early intervention program locations	2		18		3		9		5		2		10		3		52	
Communication types offered																		
Auditory-verbal	2	100	14	78	2	67	8	89	4	80	1	50	9	90	2	67	42	81
Oral/aural			9	50	1	33	3	33	2	40	2	100	9	90	2	67	28	54
Total communication	1	50	3	17					1	20			6	60			11	21
Auslan			7	39	1	33	3	33	3	60	2	100	7	70	2	67	25	48
Bilingual Auslan/English	1	50					1	11					1	10			3	6
other			1	6					1	20			1	10			3	6

This information shows that every State/Territory offers auditory-verbal programs, all States and the NT (supposedly – 'according to need and availability of resources') offer oral-aural and Auslan programs, four States/Territories offer total communication programs, and three States/Territories offer bilingual programs.

# **Statistics**

According to information available on websites about Universal Newborn Hearing Screening programs, approximately 1 in 1,000 babies are born with some kind of hearing loss.

A high percentage are now implanted early with cochlear implants.

Information about numbers of deaf and hard of hearing children in the different types of Early Intervention programs is not readily available. It is Deaf Australia's understanding that the majority are in auditory-verbal and oral-aural programs, with relatively few in bilingual programs. We are beginning to hear of parents who are enrolling their children in auditory-verbal programs and also in Auslan programs. We are also starting to hear that more parents are beginning to understand the importance of bilingual Early Intervention. However, this needs to be more fully investigated.

<sup>^</sup> Percentage of total locations in Australia.

# Service types offered

For each program location identified on the Aussie Deaf Kids website and the *Choices* booklets, information was compiled about the service types offered.

Table 6: Service types offered in each location

	ACT		NSW NT		QLD SA			TA	S	VIC		WA		National				
	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%
Early intervention																		
program locations	2		18		3		9		5		2		10		3		52	
Services																		
home visits	1	50	4	22			1	11	2	40			8	80			16	31
pre school visits	2	100	9	50			3	33	2	40					1	33	16	31
centre based	2	100	15	83			6	67	2	40			3	30	2	67	30	58
play group	2	100	14	78			3	33	4	80			1	10	1	33	25	48
parent education	1	50	14	78			4	44	1	20			6	60			27	52
itinerant/visiting teacher																		
support	1	50	1	6	1	33									1	33	4	8
outreach program			3	17	2	67	2	22	1	20	1	50	1	10	1	33	11	21
early learning groups	1	50	5	28			2	22	1	20			1	10			9	17
parent support	1	50	2	11			6	67	1	20			8	80			18	35
other													2	20			3	6

With the exception of Tasmania, for which information is not readily available, all states and the ACT offer centre based programs and playgroups. We have been informally advised that early learning groups in practice means the same thing as playgroup. Almost all of these services are in the capital cities (SE Queensland in the case of Brisbane), with a few in large regional areas – Wollongong, Bathurst and Newcastle in NSW, Cairns in Queensland. All states and the NT have access to an outreach service. Other types of services vary across states.

Many states and the ACT provide parent education and parent support. It is not always clear what these services types involve. The Shepherd Centre and Hear and Say Centre describe regular parent information nights on such topics as school readiness, managing behaviour and parenting skills. The Aurora School offers playgroups on Saturdays, parent groups, family camps and support groups.

#### Parent support groups

As well as parent information provided by Early Intervention program providers there are parent organisations and parent support groups available in many locations around Australia, usually run voluntarily by parents themselves and sometimes supported by organisations such as Deaf Children Australia. Accurate and extensive information about these groups and what they provide is not easily accessible.

Deaf Australia understands that parents need support and we advocate that this support should be more widely available and easily accessible. We also understand that for parents, sharing information with other parents is invaluable. However, there are concerns about the closed nature of many of these support groups. An enduring problem for parents is lack of reliable, unbiased, accurate and extensive information and when a parent group includes only other parents, misinformation and lack of information can be perpetuated.

Of particular concern is that parents are frequently not encouraged to or enabled to meet deaf adults. We understand that meeting deaf adults can be traumatic or counterproductive for parents if

they meet the "wrong" kind of deaf person at the "wrong" time. There are deaf people who for various reasons are angry with hearing people generally or who are not appropriately articulate in ways that parents in the early days of their support needs need them to be. However, there are ways to arrange for parents to meet deaf people who can appropriately support them.

When parents are enabled to have access to deaf people in an appropriate way this can be very reassuring for them. It can help them to see that deaf people do grow up to live rich and fulfilling lives. Getting to know deaf adults who live successfully as bilingual people can help dispel much of the misinformation and anxiety that parents often feel. Some bilingual Early Intervention programs arrange this type of contact in a controlled way.

# B. What are the gaps in early intervention services, including appropriate and effective support for family members?

# a) Types of programs

The most widely offered options are auditory-verbal and oral-aural programs. Based on numbers of identified locations, all states and territories have at least two of these programs, with NSW having 23. Of the total number of locations identified nationally, 81% offer auditory-verbal programs and 54% offer oral-aural programs.

All States and the NT claim to provide Auslan programs. Deaf Australia seriously questions the accuracy of these claims and the quality of these programs for the following reasons:

- 1. It is known that there are very few teachers of the deaf (whether deaf or hearing) with Auslan as their native or near-native language.
- 2. No State or Territory has a defined minimum Auslan competency standard for teachers of the deaf or Early Intervention workers. The National Association of Australian Teachers of the Deaf (NAATD) has a document that sets out the expected competencies for teachers of the deaf but these standards are only a guide, and in relation to Auslan, the document states only:

Demonstrate an understanding of language development

Demonstrate an understanding of theories and sequences of language acquisition in:

- Spoken language
- Signed language
- Second language
- Written language

Demonstrate an understanding of theories and sequence of communication philosophies/approaches:

- Auditory-oral
- Auditory-verbal
- Auslan
- Bilingual bicultural....

Attainment indicators for each of these competencies include certificate qualifications and/or attendance at professional development/learning.

Nowhere in the document is a standard of practical competency/fluency in Auslan specified.

3. In teacher training programs for teachers of the deaf, Auslan is not a compulsory subject, and in those programs that do include it in the curriculum, the maximum number of hours is usually around 48. Yet the number of hours required to complete Certificate IV in

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Auslan at TAFE is around 1,200. Deaf Australia considers that Certificate IV in Auslan is the minimum requirement in Auslan competency for anyone working directly in service provision to deaf people.

4. Staff working in Early Intervention programs are not necessarily teachers of the deaf. They may be speech therapists, psychologists, Auslan teachers, Social workers. There is no requirement or standard anywhere stating the minimum level of Auslan competency required for any Early Intervention workers. Even when they are trained teachers of the deaf they have not necessarily been trained specifically for Early Intervention; it is believed that many were trained initially as primary school teachers. There do not appear to be training programs in Australia specifically in bilingual Early Intervention programs for deaf and hard of hearing children. A recent review of deaf education in Victoria also highlighted that teachers of the deaf are getting older and nearing retirement age, with few new teachers being trained.

Total communication programs are provided in three states and the ACT. Total communication (or simultaneous communication as it should more accurately be identified) is being progressively discontinued in schools, and should also be discontinued in Early Intervention programs. It relies on signed English and research evidence questions the efficacy of the use of simultaneous communication (i.e., using contrived sign systems) as the basis for Early Intervention in language acquisition.

According to our two primary information sources, the Aussie Deaf Kids website and the *Choices* booklets, only two States (Victoria and Queensland) and the ACT offer bilingual Early Intervention programs. Informal advice also indicates bilingual programs are available in SA and WA, and that in Victoria the Aurora School provides Early Intervention programs in a number of locations.

Clearly there is a relative over-supply of auditory-verbal and oral-aural programs and a serious under-supply of Bilingual programs.

It is also not known how many children attend these programs, but it is believed that the majority attend auditory-verbal and oral-aural programs. Some attend a mixture of both auditory-verbal/oral-aural and Auslan programs. This needs further investigation.

#### b) Types of services

The most common types of services offered are centre based, play groups, and parent education services.

Home visits, preschool visits and parent support services are also available in just over 30% of locations.

An outreach service is available in each state and the NT.

One type of service that is missing from the Aussie Deaf Kids and *Choices* booklets information is support to child care centres, or programs based in child care centres. We have been informally advised that some program providers do visit deaf and hard of hearing children in child care centres, but this information is not readily available.

A question that needs to be asked is how useful is a service type that involves intermittent visits to preschools and child care centres. Unless there are a number of deaf or hard of hearing children in the preschool or child care centre it is unlikely that staff there will be competent in communicating with these children. If the regular staff in these centres are not able to communicate with deaf children in their care then how adequate are intermittent visits from Early Intervention workers?

# c) Information and support for parents

The most critical activity for any service for deaf and hard of hearing children is the information that is given to parents. It is parents who make decisions about what type of Early Intervention programs their children will access. Parents must necessarily base their decisions on available information and available program options. Most parents of deaf and hard of hearing children are themselves hearing with no previous knowledge of deafness.

At Deaf Australia we have been encountering for 20 years two common comments:

From service providers: "It is the parents who choose the type of program they want for their children."

From parents: "Nobody told me about that."

"That" always refers to Auslan or the Deaf community or some aspect of them.

Parents of deaf and hard of hearing children tell us that they want to make informed decisions. They want to know what options are possible and what can realistically be expected from these options, even if all of the options are not readily available locally. We hear often that parents feel they are not being supported to make this type of informed decision.

Anecdotal evidence from parents shows that the person who first tells a parent their child is deaf is the person who has most influence – it is this first message that is most clearly retained by the parent. In the Australian system the first person a parent has contact with is almost always a person with a medical perspective – a health care professional or an audiologist, especially now that early identification usually takes place in hospitals soon after birth. So the first message a parent receives, and retains above all others, is that deafness is a medical issue, with a medical 'solution'. Parents now are routinely informed very early about the cochlear implant as a 'solution' to deafness.

Governments also are informed of this. In addition, Governments are informed that the need for a cochlear implant is a medical emergency and that funding cochlear implant programs represents a potential saving on future expenses for service provision.

The cochlear implant is basically another type of hearing aid. It does not 'fix' deafness and children with cochlear implants, like children without them, usually require ongoing and long term intervention and support services. Cochlear Implant programs regularly talk about the success of the implant. But 'success' is an ambiguous term. One person's idea of 'success' can be very different to another person's idea of it. For one person, 'success' might mean that the child can hear something and has some speech. For another person it might mean that the child has good speech and age appropriate language fluency. The cochlear implant has the *potential* to enable the child to learn to listen and speak, but this potential cannot be predicted or guaranteed. Deaf Australia's concern is that the cochlear implant is being presented as a solution and children with the implant are not routinely enabled to acquire Auslan as a first language, rather they are routinely discouraged from using Auslan and are therefore at risk of not acquiring a language to native fluency.

After diagnosis parents are bombarded with complex and conflicting information and it can be very difficult for them to analyse this information and understand the biases. Many providers claim to provide unbiased information. Deaf Australia maintains that it is not possible for anyone to do this consistently and it is more important for providers and advisers to instead be upfront about their biases and why they hold them.

Australian Hearing's *Choices* booklets, which are given to most if not all parents of newly diagnosed babies and children, and the Aussie Deaf Kids website, which seems to be widely accessed by parents, both make a concerted effort to provide "unbiased" information and do a reasonably good job of it if "unbiased" means that they try to provide information from a range of points of view.

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There is also pressure on parents to choose between either signing programs or speech programs, and many auditory-verbal and oral-aural program providers claim that if the children are allowed to sign they will not learn to speak, despite there being no evidence for this claim. Naturally parents want their children to have every opportunity to learn to speak but in many programs they are being put into a position of having to reject the use of Auslan in order for their children to have the opportunity for speech therapy since oral-aural programs and in particular auditory-verbal programs do not allow the use of any kind of signing.

Deaf Australia hears many anecdotes of parents who put their children into auditory-verbal programs and conceal from the program providers the fact that they are also learning Auslan, so that the child will be permitted to remain in the auditory-verbal program. However we also hear of some oral-aural programs that do allow some limited forms of signing sometimes.

Some parents – usually those who have a family history of deafness and understand the issues, have successfully insisted on their children attending, if not a clearly bilingual program then both an Auslan program and an auditory-verbal program. However, this is unusual. It is our understanding that the majority of children are in auditory-verbal or oral-aural programs and are not exposed to Auslan. This needs to be investigated further.

Important information that we believe is rarely if ever clearly explained to parents early includes:

a) The difference between learning a language and acquiring a language and the significance of this difference; and the importance of acquiring a language to native fluency.

A deaf child exposed early and frequently enough to good Auslan language models will naturally acquire the language to native fluency in the same way and at the same rate as a hearing child acquires the spoken language used by its parents. It has been observed that with the acquisition of a first language (Auslan), the child is more likely to acquire a second language whether in spoken or written format.

A deaf child exposed only to a spoken language, even with a hearing aid or cochlear implant, is not necessarily able to naturally *acquire* the language to native fluency; they must be taught the language via speech and listening therapy. Deaf children have the potential to learn a spoken language in a monolingual environment, and there is evidence that some do. However, the probability of any particular child achieving this cannot be reliably predicted.

A great deal depends on the richness of the language environment and therefore it is vital that children are exposed early, frequently and consistently to clearly accessible language – not only in the Early Intervention program but also in the home.

For bilingual programs this means that parents and significant others must be proficient users of Auslan. Parents and immediate family members need to be enabled to learn Auslan as quickly as possible.

The importance of acquiring a language to native fluency cannot be over-emphasised.

b) The importance of integrating the 'deaf' and 'hearing' self.

Every deaf person lives their life to greater or lesser extent within an environment designed for and dominated by hearing people and the culture of hearing people. Every deaf person regardless of how they grow up and what language and communication methods they use also retains a 'self' that is deaf, and this deaf self is different from the hearing self. Early Intervention programs that deny the child access to deaf adults and Auslan prevent the child from achieving an integration of selves early on. This issue is not well researched but is clearly evident in deaf communities and many deaf people struggle with these issues later in their lives. Mental health problems are also believed to be common among deaf people.

# C. What changes need to happen?

Deaf Australia believes that all deaf children including those with only a moderate hearing loss, should have automatic and guaranteed access to bilingual Early Intervention programs. Bilingual programs, provided that they also support the family to acquire Auslan, are the only programs that allow the child to acquire a native language naturally and to also acquire a spoken language. Bilingual Early Intervention programs can and should include access to oral-aural therapy so that every child also is enabled to develop to the extent possible their ability to speak. No child should be denied access to Auslan. (Please see the attached document, *Grosjean, Francoise, The Right of the child to grow up bilingual.*)

Parents and immediate family members need to be more fully informed and more appropriately supported. Currently the options a family is able to access depends very much on where they live and in many areas there are very few if any options available locally. They should particularly be supported to learn Auslan as quickly and early as possible and this support should be guaranteed and provided at no cost to them.

The first contact person is a key person in the Early Intervention process and should not be a person presenting a medical approach as the first response.

The question of which government department should be responsible for Early Intervention also needs to be resolved. It is important that Early Intervention has an education/language development focus and not merely a health or disability focus.

Early Intervention programs need to be more widely available and more easily accessible.

Terminology and program descriptions need to be more consistent, more extensive and more accurate.

There needs to be national standards including service provider competencies and training requirements and a national monitoring system for Early Intervention programs.

# 2.2 Impacts on People with Disability

The first five years of life are crucial years for any child, deaf or hearing, for the development of language. When deaf and hard of hearing children do not receive appropriate and adequate Early Intervention they are less likely to acquire a language to native fluency. *Native language fluency* is a key concept that seems to be not well understood by many Early Intervention programs where the focus is on speech. Speech and language are not the same thing and the ability to speak does not guarantee language fluency. Deaf Australia hears of many deaf children who have not been exposed to Auslan and whose speech is "pretty good" but whose English language fluency is poor.

Without a fluent language it is difficult for a person to receive a good education. Lack of education has lifelong impacts.

The majority of deaf children are placed in Early Intervention programs that are speech based only and do not allow them to acquire Auslan. Yet Auslan may be the only language that is fully accessible to them. In later years (often around age 12 or even later) when they have not done well with acquiring English language skills they are often then moved into an education program that uses signing (not necessarily Auslan – it may be signed English), but by then the vital early language learning years are over and they then may not acquire Auslan to native fluency either.

When a child is enabled to acquire Auslan to native fluency they have a fluent language that can be used to educate them and to teach them a second, spoken, language (English). Bilingual programs also address the needs of the whole child, not merely the development of speech.

In addition, in bilingual programs that present both languages equally to the child, including supporting family members to develop Auslan proficiency, some children will develop language proficiency equally in both languages, while some will be dominant in one language and use the other as a support. Since it is not possible to reliably predict language outcomes, bilingual Early Intervention programs offer the strongest 'safety net'.

# 2.3 Impacts on Carers / Family Members

When families cannot communicate effectively with a deaf child, family relationships are affected.

Most families with a deaf child are hearing families and do not automatically have a common easily shared language that enables age appropriate communication to occur naturally.

Because the family's language is usually English, and because families are informed that deaf and hard of hearing children have the potential to learn to speak, many families choose the monolingual English option over the use of Auslan or bilingual approaches.

Although deaf and hard of hearing children have the potential to learn to speak and some do achieve this, generally it takes a deaf child much longer to acquire a fluent spoken language than a signed language because a signed language is fully accessible to them whereas a spoken language is only partially accessible.

When families have access to Early Intervention programs that enable the child to acquire both spoken and signed languages and that also enable the family to acquire signed language, then the family has at least one common language (Auslan) that they can use to communicate effectively with the child from the beginning. This early effective communication is vital for language, cognitive and social development of the child and for healthy family relationships.

Unfortunately in Australia programs to support parents and other family members to learn Auslan are not widely available or funded. We understand that some countries, notably Sweden, provide and fund this type of sign language learning support for parents of newly diagnosed deaf children. Unfortunately information about the Swedish program is not readily available.

# 2.4 Supporting Evidence

The following list is indicative of the research available but is far from exhaustive. Many authors on this list have written extensively on Early Intervention and language acquisition and only some of their relevant work is listed here.

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#### 3. Advice

# 3.1 Advice to Government / Department

Deaf Australia believes that the Australian Government should establish a national panel to develop a national plan for the widespread provision of world's best practice bilingual Early Intervention programs including support programs for parents and immediate family members.

This panel should be largely composed of experienced bilingual educators, deaf people who are successfully bilingual, and parents who accept the deaf child's right to be bilingual. It should not be over-weighed by medical, therapy, or social/welfare professionals as most Universal Newborn Hearing Screening related programs currently seem to be.

Medical and technological assistance (e.g., hearing aids and cochlear implants) and therapy programs (e.g., oral-aural therapy) have a place in Early Intervention programs but Early Intervention programs should not be limited to these approaches.

In developing a national plan, the panel should conduct a full investigation of the current situation for Early Intervention for deaf and hard of hearing children in Australia, and research world's best practice, including support programs for families.

The national plan should include:

- establishing national standards for Early Intervention programs for deaf and hard of hearing children, including requirements for competencies and training for personnel working in Early Intervention programs;
- making terminology and descriptions of services and approaches more consistent;
- a requirement that deaf people be included in Early Intervention programs (with support for their training where needed);
- better articulation of the goals of Early Intervention programs for deaf and hard of hearing children, i.e., acquisition of a language to native fluency as much as possible, and acknowledgement that this can be either English or Auslan (or both) – just as many hearing children are exposed to more than one language and acquire them effortlessly if the input is accessible and meaningful;
- working with families of deaf and hard of hearing children so that the deaf child is included
  and accepted in the family system and other members of the family are able to communicate
  with him/her. This should include a funded program that enables the family to learn Auslan
  as quickly and early as possible.

#### Notes

- 1. This paper uses the term 'Deaf and hard of hearing' in line with an agreement between the two international organisations, World Federation of the Deaf and the International Federation of the Hard of Hearing. Many people in Australia continue to use the term 'hearing impaired' instead of 'hard of hearing'.
- 2. This paper does not cover Early Intervention programs for children who are deaf/blind or who are deaf and have additional disabilities. Early intervention services for these children also need to be investigated.