

## Introduction & Executive Summary

SCIC is Australia's largest cochlear implant and related technology provider with over 2500 clients and service coverage across NSW and ACT. SCIC is the state-wide provider for adults and children services in both the ACT and NSW. Additional services are provided in remote and rural Australia including the Northern Territory.

SCIC provides seamless access to all diagnostic and implant hearing services from newborn to elderly clients and funding for acute and non-acute services is provided through government (state and federal), private insurance and charity.

Australia has had an excellent Commonwealth Hearing Services Program in existence since 1947 providing services to children, pensioners and war veterans. Today however, there are large numbers of deaf and hearing impaired Australians that are not eligible for these services and who are struggling to manage their hearing loss.

The Commonwealth Hearing Services Program, which focuses in the main, on hearing aid technology, is limited in its ability to extend appropriate services to meet the need of the significant hearing loss clients where implantable medical hearing technologies are indicated. This "gap" in its service is managed within state based health services but the approach by the individual states is inconsistent.

SCIC has responded to the needs of those requiring implantable technology by bringing together the surgical and non surgical services and integrating both State and Federal support mechanisms to achieve a high standard of outcome for the client. Recent trends towards bilateral cochlear implants, upgrades and replacement devices, hybrid, BAHAs and alternate implantable hearing devices support the case for a comprehensive review of services and support capturing and properly integrating the newer developments in hearing treatment.

The degree of hearing loss is commensurate with the level of disability. The greater the level of disability, the more effective the application of current technologies in mitigating the disability. Yet it is very much at this significant hearing loss level where services are most inconsistent and in need of improvement. This review should consider how resources can be directed to give maximum assistance to those afflicted with the most significant loss.

### SCIC recommends the review considers:

- Increased public funding at a state level for surgery, implantable devices and assessment / rehabilitation that enables timely access to appropriate implantable technology and related services for those with significant hearing loss
- All services should be geographically available in areas of demand
- Funding should be made available for bilateral cochlear implants and hybrid devices in children and in specific cases for adults
- Funding for upgrades / replacements to speech processors, should be extended to adults eligible under, Commonwealth Hearing Services Program provisions through amendments to the Declared Hearing Services Determination 1997, amended 2007.

- Funding for adults who are not eligible for the Commonwealth Hearing services Program to assist with purchase of services and devices should be made possible and based on the degree of disability and income
- Awareness and research programs, both preventative and treatment oriented, should receive additional support.
- Alternative service models be developed and implemented for indigenous Australians to complement the work presently being undertaken.
- Improved access to public funded diagnostic audiology services to enable all children and adults to be referred for appropriate and timely intervention

SCIC would welcome the opportunity to present to the Senate enquiry to provide further information to this important review.

## **The Sydney Cochlear Implant Centre (SCIC)**

The SCIC is Australia's largest cochlear implant centre established in 1984 and the world's largest user of the Australian developed Nucleus cochlear implant system. There are over 2500 existing SCIC cochlear implant recipients and an additional 350 new clients assisted each year through SCIC.

SCIC hubs the cochlear implant interests of NSW and ACT Health, The University of Sydney and 2 charities, SCIC Ltd and CCIC Inc. SCIC works across 12 hospitals and 20+ outreach sites and has permanent sites in Gladesville, Newcastle, Canberra, Gosford in addition to outreach support for the Northern Territory. SCIC works to ensure equitable access to the cochlear implant and related implantable hearing technologies for public, private and charity clients.

Research has shown that implantable hearing solutions today are the expected intervention utilised for severe to profound bilateral hearing loss clients and for specific aetiologies causing moderate hearing loss or unilateral deafness.

The advent of hybrid cochlear implants, bilateral fittings, bone anchored hearing aids, other emerging technologies and threshold changes in fitting criteria has seen service of the SCIC become extremely broad in nature and geographically diverse.

SCIC is committed to seeing access grow for hearing services and technologies to meet the growing needs of clients existing and new regardless of geographical or financial considerations.

### **All Age Service**

Many cochlear implant clinics are limited to children OR adults in their infrastructure. SCIC provides services for all ages from newborn children to adolescents, young adults through to the elderly. This approach allows us to look after the clients needs for life. SCIC has children mere months of age to adults over the age of 100 years.

### **Surgical Expertise**

Professor Gibson AM is the world's No.1 cochlear implant surgeon having conducted over 1500 surgeries. Professor Gibson heads a surgical team of 9 specially trained implantable hearing specialists (ENT Surgeons) across 12 hospital sites. Surgical services are geographically spread and partnered with all other SCIC services for quality and access

### **Diagnostic Expertise**

SCIC has pioneered many of the world's best objective hearing test procedures assisting in accurate diagnosis of the extent of hearing loss and the area of compromise leading to optimal outcomes and device and rehabilitation selection.

### **Research**

SCIC is at the forefront of hearing research with particular focus on improved outcomes using new and existing technologies. SCIC has dedicated undergraduate, post-graduate, PhD and Medical Fellowships designed to optimise outcomes, improve treatment and rehabilitation approaches and

professional standards in the field. SCIC is a supporting party to the Hearing CRC. SCIC is affiliated with the University of Sydney, Macquarie University and Newcastle University.

### **Newborn Screening**

SCIC is a tertiary diagnostic site and works closely with NSW and ACT health within their newborn screening programs. SCIC General Manager and Surgical Director are also on the NSW Health Ministerial Standing Committee – Hearing Services charged with overseeing the effective implementation of the SWISH program in addition to other responsibilities.

### **Management Expertise**

SCIC Executive and management have significant experience working with stakeholders including State and Federal Government, private health and insurance companies, sponsor and funding groups and recipient network agencies and peak industry bodies. This expertise ensures the on-going nature of services, equitable access, support for clients, upgrades and optimisation of the funding mechanisms important for growing client numbers.

### **Private / Public and Charity Funding (Veteran's Affairs, Workers Comp)**

SCIC acute services are funded via:

- Public Health (NSW and ACT)
- Private Client Insurance
- Veteran's Affairs (Commonwealth)
- Federal Funding (OHS and Australian Hearing)
- Charity (SCIC Ltd, CCIC Inc and Private Trusts and Foundations)

Charity funding supports cochlear implant device provision, rehabilitation and assessment services, facilities and infrastructure and ongoing growth of the service.

### **Technologies**

- Cochlear Implants (Cochlear Ltd, MedEl and Advanced Bionics)
- Bone Anchored Hearing Aids
- Hybrid Systems (Cochlear Ltd and MedEl)
- Vibrant Sound Bridge (MedEl)
- Auditory Brain stem implants

### **Lifetime Support / Spare Parts / On Call**

SCIC provides a comprehensive service for all age groups for life. Utilising specially trained technicians maintenance support is for all clients irrespective of location and is accessible and timely. Our on-call service gives comprehensive, medical, device and outcome support to all recipients. SCIC has a large inventory of spare parts for all commercially available devices, loaner speech processors and equipment and access to the manufacturers for speech processor repairs. SCIC works closely to ensure a quality outcome for those under Australian Hearing Services Card arrangements.

## **Upgrades**

SCIC works closely with private health providers, Veteran's Affairs, insurance companies, and government to provide upgrades for cochlear implant recipients. Additionally the SCIC Charity supports upgrades where other options are not available. Speech processor upgrades become available on average every 3-5 years and there are often many functional hearing benefits and advancements to be achieved through updating of the technology. As most cochlear implant recipients use their device for all their waking hours there is considerable wear and tear on the speech processor. Speech Processors have a life of approx. 3-5 years, upgrading or replacement of dysfunctional technology ensures continual functioning of optimised hearing.

Private Health providers vary in their support of speech processor upgrades and SCIC management actively engage all providers to ensure optimal support where real benefit can be demonstrated.

## **Integrity Testing**

SCIC is the only cochlear implant provider in Australia and one of only 2 in the world that has been credentialed to perform cochlear implant integrity testing to ensure optimal device functioning, timely diagnosis of faults and compromises that may have a significant impact on the cochlear implant recipient. Information gained from the integrity test is used to optimally manage the device for a client or as part of the decision making process to recommend the ex-plantation and re-implantation. Capturing cochlear implant device compromise within the 10 year warranty period may save cost to the health system, client and / or program.

## **No Cost Service**

SCIC does not bill clients for cochlear implant services. Costs are generally covered through public state funding, private health, charity or federal government provisions including bulk billing arrangements of Medicare where appropriate. SCIC is a "no-Gap" surgical service where private health is in place.

## Reference Questions

### a. The Extent, Causes and Cost of Hearing Impairment in Australia

This prevalence, cause and cost of hearing impairment in Australia is well documented within many report and publications, the most comprehensive being the Access Economics "Listen Hear" report published in February 2006.

In summary the report says;

- 1 in 6 Australians are affected by hearing loss (1% for people < 15 years to 75% for people aged > 70 years)
- Hearing loss can be caused by structural defects within the middle ear (conductive hearing loss) or damage within or malformation of the cochlea (sensorineural hearing loss)
- The real financial cost of hearing loss has been estimated at \$11.75billion or 1.4% of GDP. This includes a \$6.7billion productivity loss but doesn't include the disease burden cost of a further \$11.3billion.

It should be noted that clients seeking the services of cochlear implant clinics, such as SCIC, are from the 11% of the hearing loss population with severe to profound deafness, Figure 3-6 Access Economics P.34.

These clinics are managing and providing services to the client group where the impact of hearing loss is most significant on their daily ability to communicate. It is estimated that 90,200 people have a severe hearing loss in the better ear and 400,000 with a severe hearing loss in the worse ear. The greater the age, the more prevalent this disability. (Access Economics Table 3-4 & 3- Prevalence, hearing loss by severity, gender and age).

In Australia there are approximately 6,000 children and adults with Cochlear Implants today. Based on the Access Economics data and considering those with severe hearing loss in the better ear there are approximately 84,000 people who would potentially benefit from cochlear implantation and / or other implantable hearing devices.

With the advent of Universal Newborn Hearing Screening in most states, children usually receive the appropriate intervention through Australian hearing and timely referral to cochlear implant clinics.

Children and young adults under 21 years of age receive access to specific hearing services, upgrades and replacement speech processors, spare parts and maintenance services, all pensioners (age, DVA and disability and Commonwealth Rehabilitation pension) receive the above however speech processor upgrades and replacement devices are not available. SCIC firmly believe this provision is inconsistent and should be reviewed to enable upgrades and replacement devices.

An appropriate extension to the provisions under the Commonwealth Hearing Services Program would be to enable assessment of degree of disability / income and other criteria in order to access appropriate assistance for services. The following recommendations are made;

- Increased public funding for implantable technologies and surgical space within public hospitals

- Adoption of the UK NHS system where bilateral cochlear implants are available for all children and adults that meet agreed criteria.
- Funding for speech processor upgrades and replacement devices be extended to all adult clients eligible under the OHS Act including new and emerging technologies
- Consideration be given to providing affordable devices and services to deaf and hearing impaired using the following criteria:
  - Students > 21 years
  - Individuals on unemployment benefits
  - Individual on sickness benefits
  - Individuals on low income
  - Self- funded retirees
  - Previous child clients of Australian Hearing, mainly the congenitally deaf.

#### **b. The Implications of Hearing Impairment for the Individual and the Community**

A loss of hearing limits an individual's ability to communicate and interact with society. The more severe the hearing loss the greater the reduction in communication which frequently results in social isolation.

When hearing loss is evaluated against degrees of severity with other conditions it should be considered a national priority. The more severe the loss the greater the priority.

*Access Economics: In Terms of disability weighting severe hearing loss is comparable to having pneumonia on an ongoing basis.*

Hearing loss is usually described as either congenital (at birth) or an acquired loss.

With congenital hearing loss a child's ability to develop speech and language will be significantly restricted unless appropriate early intervention is available in the first 12 months of life. A child's competency with speech and language will significantly affect their chance of being a productive contributor to the community. Research shows approximately 27% of children with hearing loss have an additional disability.

The implementation of Universal Newborn Hearing Screening (UNHS) programs in a number of states and the ACT has successfully achieved the goal of lowering the age on intervention from 2 years to < 6 months. There are still some children being missed as a UNHS program has not been implemented in Victoria and Western Australia and only partially implemented in the Northern Territory.

Only a small number of adults and older children acquire a hearing loss suddenly. Generally an acquired hearing loss is caused by progressive deterioration over many years. Adults with acquired severe hearing loss are frequently referred to as long term deafened.

Long term deafness has significant impact on a person's ability to work thus reducing their chance of a decent income and savings and subsequently access to affordable hearing services and devices.

*"I have frequently had politicians say that they should be encouraged to take out Private Health Insurance, in most cases this would be 10% of their total income for a year and would be out of reach for anyone on a pension or unemployment, sickness benefits or a student".*

**c. The Adequacy of Access to Hearing Services, including Assessment and Support Services and Hearing Technologies**

**Hearing Technologies**

Whilst the Commonwealth Hearing Services Program makes appropriate provision for conventional hearing aids, initial implantable hearing technologies and associated assessment and intervention fall into the domain of the state health systems, charity and private providers. SCIC hubs the NSW and ACT State allocations for cochlear implants and combines with private insurance companies, Worker's Compensation Insurance, Veteran's Affairs and charity to provide its services.

Emerging trends in cochlear implantation of broadening criteria in addition to new devices such as Bone Anchored Hearing Aids (BAHA), Hybrid devices combining acoustic and electronic hearing signals, Auditory Brainstem Implants (ABI) and other technologies are not readily accessible to uninsured clients. This should be addressed immediately as a focal point of this review.

SCIC is an established program that combines the acute in-hospital access with pre and post assessment and rehabilitation services.

**Acute In – Hospital Access**

For acute cochlear implant in-hospital services, access varies from state to state and from adults to children. Children in NSW and ACT have reasonable access to single sided cochlear implant technologies under public / private and charity funding models dependent on age, whilst adults have poor access compared to incidence. Under current provisions it should be noted the older age groups are the most disadvantaged compared to the youngest where newborn screening through to cochlear implantation is generally accessible.

**Acute – Rehabilitation and Audiological Services (Pre and Post-operative)**

Services to assist the optimisation of implantable hearing devices are not consistently funded nationally. SCIC has a heavy reliance on limited state health and charity funding to provide comprehensive acute assessment and rehabilitation services for cochlear implant recipients.

**1. Children's Services**

Access for acute cochlear implant services for children when utilising all appropriate funding sources (Public, private and charity) is timely and comprehensive in both NSW and ACT. However this is for clients satisfying criteria for unilateral cochlear implantation at severe to profound hearing loss levels. Add hybrid, bilateral and expanding criteria and the existing model is grossly inadequate.

Commonwealth support for spare parts, maintenance, upgrades and replacement devices exists for eligible children under the Commonwealth Hearing Services Program up to the age of 21.



With the advent of universal newborn screening it is critical to ensure timely access to hearing tests etc via Australian Hearing services network.

### **Children's Rehabilitation Services**

Children require acute rehabilitation services post operatively in order to make use of the new hearing with a cochlear implant, overcome developmental delays associated with deafness and learn speech, language and communication. SCIC provide this comprehensive service to all children however it should be noted this is in addition to early intervention and continued educational support offered by external government and non government agencies. Recent significant changes have limited the access to some external agencies. This has resulted in the need for SCIC to extend the acute rehabilitation services it offers and this has a significant cost implication to the program's charity funding.

Limited NSW Health funding is available for specific aspects of assessment and post operative rehabilitation with charity funding being the principal funding source for the extensive teaching / speech and hearing and audiological services required for optimal outcomes.

### **Other Important Services**

Timely hearing testing conducted by Australian Hearing, state hospital based audiology outpatient clinics and private / non government providers (including charity) is critical to early management and consideration for a cochlear implant. Recently we have noted the closure or significant reduction of audiological services by state based hospitals and this has increased demand on the remaining providers including SCIC. Some non-government providers have instigated a "co-payment" arrangement and this will no-doubt increase the load on Australian Hearing. This is an area in need of strategic consideration.

Quality psychosocial support is critical to family and recipient support and not generally offered by Australian Hearing. Some counselling support is linked to the NSW State Wide Infant Screening – Hearing (SWISH) program however these part time positions have generally been hard to fill. SCIC provides this service for paediatric clients.

## **2. Older children**

Older children obviously do not access "early intervention" as part of their education however many of these clients are fully integrated into mainstream school using conventional hearing aids when the "changeover" to the cochlear implant. Many older children may receive support from state government or charity supported "itinerant" teachers. A child entering the SCIC service for "changeover" requires acute rehabilitation in order for them to make sense of their new hearing signal and this role is provided by SCIC from funds sourced from the SCIC charity.

### **Other important services**

See note "Other important services" above.

### **3. Adult Services**

Adult funding, even under SCIC public, charity and private access is grossly inadequate for unilateral cochlear implantation at severe to profound levels compared to significant hearing loss incidence and considerably worse if the criteria widens to hybrid, bilateral or lesser hearing losses. As such, SCIC only captures “known referred clients” as increased awareness creates extended waiting lists for services that cannot be met in any realistic timeframe. Presently waiting lists for “known referred clients” is approx. 12 month. Whilst it is noted that access for adult clients is better in NSW and ACT than the national average, it is far from meeting the incidence of deafness at even severe to profound hearing loss levels.

There is no state government reimbursement for assessment or post operative rehabilitation services for adults and funding is provided through appropriate and limited bulk billing arrangements under the surgeon provider number or through the SCIC charity.

#### **Other important services**

Timely hearing testing conducted by Australian Hearing, state hospital based audiology outpatient clinics and private / Non government providers (including charity) is critical to early management and consideration for a cochlear implant in adults. Many of the adult clients seeking audiological services do so via the private providers however some private providers may be reluctant to “hand-over” clients who may meet implantable hearing technology referral criteria to implant specialists as it will reduce their revenue. This is not generally a concern with complex clients under Australian Hearing management as quality referral pathways exist. Access to timely services with Australian Hearing may still be a problem for complex clients who should be managed exclusively by Australian Hearing / OHS.

Quality psychosocial support is critical to adult recipient support and Australian Hearing is not sufficiently resourced to offer this service. SCIC audiologists spend considerable time counselling adults on the psychosocial issues associated with hearing loss through cochlear implant evaluation. The SCIC audiologists work with CICADA (cochlear implant support group) to mentor potential candidates through the process.

#### **Funding of State Hearing Services**

SCIC strongly advocate improvement to state based audiological services to enable equitable geographical access to appropriate services. This could be achieved through:

- Commonwealth funding for State based Audiology services enabling access via state health regions
- The introduction of a Medicare rebate for audiologists similar to optometrists.
- Improvement to the private health rebate for hearing services including audiological tests and assessment.

#### **d. The adequacy of current hearing health and research programs, including education and awareness programs,**

SCIC has a significant involvement in research in the field of hearing loss, treatment and technology. SCIC conducts independent research, has several collaborative research partners



and supports professional development including sponsorship of PhD positions. SCIC is a supporting partner of the Hearing CRC and will be part of the Macquarie University Hearing Hub.

SCIC works in with established awareness campaigns such as Hearing Awareness Week and Deafness Forum and other peak bodies to improve the understanding of hearing loss, treatment options and preventative approaches.

SCIC works closely with consumer groups such as CICADA in raising awareness of the benefits of cochlear implantation and mentoring severe and profoundly deaf clients exploring the possibility of a cochlear implant. The latter is a very effective way of assisting individuals in the decision making and through the process.

SCIC also provides educational seminars to and in-service educator, audiologists and other professionals and consumers throughout the year. These services are usually supported by charity funding and sponsorship.

Awareness and research programs both preventative and treatment oriented should receive additional support.

#### **e. Specific Issues Affecting Indigenous Communities**

Alternative service models be developed and implemented for indigenous Australians to manage the high prevalence of middle ear hearing loss (mild/moderate) present in indigenous children in most communities in the first 12 months of life. Early intervention in resolving the health issue as well as the speech and language delay resulting from ongoing hearing loss needs to be available and sustainable in the first 6 months of life.

A small proportion of these children will be born with severe to profound deafness and a number will acquire a severe hearing loss in the first few years of life usually from chronic middle ear disease or meningitis. These children would benefit from cochlear implantation if they have access to appropriate cochlear implant services, early educational auditory therapy and the necessary support mechanisms to enable compliance with treatment.

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