

# Cochlear Implant Access in Six Developed Countries

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**Background:** Access to cochlear implantation varies greatly around the world. It is affected by factors that are specific to each country's health care system, by awareness, and by societal attitudes regarding deafness.

**Methods:** Cochlear implant clinicians and researchers from six countries explored and discussed these variations and their likely causes: Robert Briggs from Australia; Wolfe-Dieter Baumgartner from Austria; Thomas Lenarz from Germany; Eva Koltharp from Sweden; Christopher Raine from the United Kingdom, and Craig Buchman, Donna Sorkin, and Christine Yoshinago from the United States.

**Results:** Utilization rates are quite different for the pediatric and adult demographics in all six countries. Pediatric utilization ranges in the six countries (all in the developed

world) ranged from a low of 50% in the United States to a high of 97% in Australia. Adult utilization is less than 10% everywhere in the world.

**Conclusions:** Pediatric access to care was excellent for children with the exception of Germany and the United States where there is an inadequate referral system. Adult utilization was low everywhere because of the lack of screening for adults and the fact that primary care physicians and even audiologists are unfamiliar with CI candidacy criteria and outcomes, and hence typically do not make patient referrals. **Key Words:** Access to care—Awareness—Cochlear implants—Utilization.

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Access to cochlear implantation varies greatly around the world because of country-specific factors. This study explores access factors in six developed countries and reflects insights provided by representatives of those countries during a panel convened at the 14th Symposium on Cochlear Implants in Children held December 2014 in Nashville (TN). Each of the six countries examined had advanced health care systems and active cochlear implant programs; nonetheless, there was variability between countries in terms of utilization rates and even within each country based upon the age of the patient population.

## PEDIATRIC ACCESS

Universal newborn hearing screening is now in place in most developed countries including all six of the countries represented on the panel. All six countries indicated that 90% or more of infants are now screened for hearing loss in the first month of life (1). This provides the opportunity to identify many more children with hearing loss who are candidates for cochlear implants early on and has also provided a vehicle through the health care system to deliver information to families.

Having a comprehensive database for children has provided parents with the information they need to move forward with cochlear implantation for their children at an early age, if they wish to do so. For example, in Australia state-based parent advisors follow up with families after a baby fails the newborn hearing screen. This process provides a largely consistent outcome of families seeking cochlear implants for their young deaf children throughout all regions of the country.

The highest rate of CI utilization in young children among those countries represented on the panel was in Australia where an estimated 98% of candidate children birth to 2 years of age received cochlear implants in 2013. Utilization rates decline dramatically to 18% for children 3 years and older. The Australian estimates are based upon prevalence of severe to profound hearing loss in various age ranges (2). Universal newborn hearing screening and the system of healthcare reimbursement accounts for the very high rates of utilization in young children. Much lower rates of penetration in older children and especially adults reflect the deficiencies in referral pathways and the constraints in public funding for hospitals.

Three of the countries represented on the panel (Australia, Sweden, and the UK) indicated their countries have pediatric CI utilization rates of 90% or more, in large part because of parent information and timely referrals after newborn hearing screening. Two countries were the exception to the high pediatric utilization: 1) in

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Germany, CI utilization by young children is approximately 65%, largely because of counseling issues and 2) in the United States, pediatric utilization was cited as 50% by one panelist calculated from national prevalence estimates (3).

Another US panelist noted that their data, based upon the National Early Childhood Assessment Project or NECAP (4), showed utilization rates of 59% among children with profound hearing loss and 51% for those in the severe hearing loss category. The data were drawn from 12 states participating in the study. Yoshinaga-Itano's data for one state, Colorado, indicate that 86% of children with profound hearing loss and 71% of children with severe hearing loss received a cochlear implant by 7 years of age (5). The much higher Colorado penetration demonstrates the effect of providing families with comprehensive information as well as the considerable diversity in utilization across the United States.

The US system of early intervention advisement is state-based but unlike Australia's system, it varies greatly from state to state in terms of the nature of information provided. Rather than delivering comprehensive, evidence-based information on language development options, the US system is heavily influenced by the individual state agencies' approach to deafness and even by the individual perspective of the early intervention professional who provides services to families; hence there is great variability in the nature of information provided (6). Parent advisors in some US states (e.g., North Carolina and Colorado) seem to consistently provide comprehensive information to families, resulting in higher rates of utilization whereas interventionists from other states omit or discredit the cochlear implant option. There are no known differences in candidacy criteria utilized by states or areas of the country as most public and private health insurance entities use the FDA candidacy guideline. Hence, the differences we observe are likely because of referral behaviors.

The authors representing ACI Alliance think that such discrepancies in the accuracy and completeness of information provided lay the foundation for the relatively low rate of pediatric CI utilization in the United States. There is a perception that the lower utilization rate is because of the US insurance system. Although there are still some individuals and families without insurance coverage for cochlear implantation, this is not a significant issue given pediatric CI coverage under the range of insurance vehicles offered. Medicaid, private employer health insurance plans, military plans, and Marketplace plans offered under the Affordable Care Act (aka "Obama-Care") all cover the cochlear implant intervention with a very few exceptions (3).

### ADULT ACCESS

Although pediatric utilization was 90% or higher in Australia and many European countries, adult CI utilization was extremely low in all of the countries represented on the panel. This was true despite cost

effectiveness of CI in adults (6–9). An estimated 5 to 7% of eligible US adults receive cochlear implants (3). European estimates for utilization are similar or even lower. Despite very high pediatric penetration in Australia, that country's adult rate ranged from a low of 0.3% for the 65 to 74 years of age demographic to 5% for young adults 18 to 29 years of age (2).

Low adult utilization was attributed to a number of issues including a lack of screening for hearing loss in adults. If adults were widely screened, a finding of severe-to-profound hearing loss might serve to create a channel for referrals, just as newborn screening does in young children. Primary care physicians in all of the countries represented on the panel generally do not refer patients to hearing care professionals, for either hearing aids or cochlear implants. Most are unfamiliar with CI candidacy and outcomes. The referral issue is further complicated by the fact that physicians and other health care professionals often do not view hearing loss in adults as a significant health issue. Although adults with mild to moderately severe hearing loss use hearing aids only 50% of the time or less, the majority of those with greater levels of hearing loss are likely to use amplification. For adults with severe or profound hearing loss, the estimated utilization rates were 70% and 90%, respectively (10). This is the population who are possible candidates for cochlear implants. As with pediatric insurance coverage, the majority of health insurance plans cover cochlear implantation in adults with the one exception being Medicaid, which covers adults in only approximately half of the states.

Panelists noted that even audiologists and other dispensing hearing care professionals generally do not refer in a timely manner (if at all) and tend to keep patients in hearing aids longer than they should. Hearing aid dispensers are often unfamiliar with cochlear implant candidacy criteria and outcomes, which contributes to infrequent referrals.

The panelist from the UK noted that hearing aid dispensers (including audiologists) perform hearing tests and fittings with the most powerful hearing aids available, though many such patients should be referred for a cochlear implant evaluation. To better understand this environment and analyze possible options for improvement, their Yorkshire clinic surveyed audiologists in the region. Hearing care professionals were provided with various audiograms and asked whether hypothetical patients were CI candidates. The clinic team was surprised by the lack of knowledge regarding CI candidacy, even among audiologists. They conducted CI tutorials, which was a successful approach and resulted in a doubling of adult referrals in the region. Hence, within their patient population, an educational effort did help with increasing referrals from within hearing health care.

In Australia, primary care physicians are generally familiar with cochlear implants in part because of the prominence of Cochlear Ltd as a successful Australian company operating in a world market. The problem lies in their not knowing the candidacy criteria and hence

when to refer. In Austria, it was noted that despite many lectures given on cochlear implantation, there has been little improvement in referrals. Other panelists agreed that little understanding regarding CI exists within general medicine and that referrals from this channel are unusual.

### HEALTH CARE SYSTEMS' PROVISION OF COCHLEAR IMPLANTS

The panelists' countries were diverse in terms of the financial models used to provide cochlear implantation. In the UK, the process of covering cochlear implants began with a charity-based system in the late 1980s. As studies and reports became available on outcomes, coverage was initiated with the National Health Service (NHS) in 1994. As numbers of recipients grew, lawmakers began questioning the cost of providing the service vis-à-vis benefits. Clinical scoping was established by the National Institute for Health and Clinical Excellence (NICE) in 2006, which resulted in having standards that insurers follow (11). These are different for adults and children with the adult standard being more stringent than the pediatric one; for example, adults are typically not covered for bilateral cochlear implants though children are. Additionally, candidacy criteria for unilateral cochlear implantation in the UK are more stringent than those in the United States and in some European countries. Thus far, the numbers of allowed CIs have not been capped and have been fairly stable at 1200 to 1300 per year (12).

In Germany, there is a multiple payer system that includes public health insurance entities (which everyone must belong to) and private insurance plans, which cover approximately 11% of individuals and are comparable to the US system of employer-provided plans. Guidelines for coverage are developed by the various medical societies, which are generally adopted by the above and used to determine who may receive various interventions including cochlear implants. There have been some disputes on bilateral cochlear implantation and single-sided deafness. When this occurs, the case is brought to court; in general, these decisions have been quite favorable for cochlear implants because the law stipulates that insurance must cover what is considered optimum care.

The US system has diverse players involved; private employer plans are the largest category and cover 54% of individuals. Government plans cover another 34% of the population and include Medicare (for people over age 65), Medicaid (serving low-income families), and Military plans. The new Marketplace plans were initiated as part of the Affordable Care Act and covered 15 million Americans in 2014; this has served to decrease the proportion of uninsured people from 18 to 13.4% (13). (Note: Because of overlaps, the percentages do not add but this does still provide a rough picture of the breakdown.) The majority of US insurance vehicles use FDA coverage guidelines, the one exception being

Medicare, which currently has a more limited scope of coverage.

### POLITICAL ISSUES ASSOCIATED WITH DEAFNESS

One other factor that is difficult to quantify but which we know affects perceptions of cochlear implants in the United States is the information on cochlear implants shared by organizations and individuals who identify with Deaf culture. The Deaf community continues to provide negative and inaccurate information regarding cochlear implants in children. This continues to confuse the general public and also serves to discourage pediatricians and even family doctors from mentioning the intervention by inserting a negative perception of the intervention (3). Parents are often encouraged to have their child learn sign first and wait on "brain surgery" until the child is older (6). This results in many children coming to CI clinics too late to enjoy optimal outcomes, or not pursuing the CI option at all. This factor is a purely American phenomenon and was not thought to be a major issue in any of the other countries represented on the panel.

### ACCESS CHALLENGES REMAIN

The six countries represented on the panel were providing excellent access for children with the exception of Germany and the United States. In both of the latter instances, the reason was an inadequate referral system. For adults, utilization was low everywhere. The reasons are associated with the lack of hearing loss screening and the fact that primary care physicians and even audiologists are unfamiliar with CI candidacy criteria and outcomes, and hence typically do not make patient referrals. Adult access in some countries, including the UK and Australia, is impeded by stringent candidacy criteria and rationing (i.e., placing candidates on wait lists). Hearing loss is not addressed as a health care issue, a situation that may be helped by an increasing number of studies that demonstrate quality-of-life improvements as well as an association between dementia and hearing loss.

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