

SWITCHED ON FOR LIFE:

benefits for children from access to hearing loss care

EUROPEAN REPORT



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Acknowledgements

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HEARRING is a learning network of collaborative experts in the field of hearing implants. Cooperation between HEARRING network members emphasises:

- World-class medical care, surgery, (re)habilitation and long-term patient care
- Superior patient advising and consultancy
- State-of-the-field research
- Outstanding training and education
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What do we mean by... ?

- **Cochlear implant:** An electronic device, a portion of which is surgically implanted into the inner ear, which is designed to provide a sensation of sound to severely hearing impaired or deaf individuals.
- **Hearing impairment:** A general term used to describe any disruption in the normal auditory process.
- **Unilateral hearing impairment:** Pertaining to only one ear or one side of the head (i.e., the person with a hearing loss on the right but not the left has a unilateral hearing loss.).
- **Bilateral hearing impairment:** Both ears or both sides of the head are involved (i.e., bilateral hearing loss.).
- **Severe hearing impairment:** There are various degrees of hearing loss: one commonly used scale is: mild = 25 to 40 dB, moderate = 41 to 55 dB, moderately-severe = 56 to 70 dB, severe = 71 to 90 dB, and profound = greater than 90 dB.
- **Pre-lingual deafness:** Hearing loss that occurs prior to a child developing speech and language skills.
- **Pure tone average (PTA):** The average of the air-conduction thresholds of the three middle frequencies, usually 500 Hz, 1000 Hz, and 2000 Hz. For flat or gently-sloping shaped hearing losses the Pure Tone Average often correlates with the Speech Reception Threshold. Sometimes the average includes other combinations of frequencies (i.e., a high frequency average may include 3000 Hz or 4000 Hz).

(((beat)))
the silence

Note:

This report has been developed by a range of global experts in the field of hearing loss in partnership with an educational grant from MED-EL. All the content in this report has been informed by the opinions and guidance of the HEARRING expert group and the support of Beat the Silence (Beat the silence is a not for profit organisation aiming to overcome hearing loss as a barrier to communication and to offer help). The report offers a consensus of opinion on hearing loss in children and should not be interpreted as a direct representation of the views of any one party.

MED^{EL}

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In Brief

Hearing impairment impacts the lives of children

The lives and future prospects of children can be particularly impacted by hearing impairment. Hearing is vital to language and speech development and learning. Hearing loss impacts the education and development of children, increasing educational costs, reducing their potential to lead productive lives.

With this in mind, we developed this report with the HEARRING expert group. It throws the spotlight on the challenges and indeed opportunities for children with hearing impairment.

What is the issue?

- The WHO estimates that between 0.5 to 5 in every 1000 children worldwide are born every year with or develop hearing impairment.
- Studies show that 4 to 11 in 10 000¹ school children are affected by severe hearing loss in their early childhood.
- Hearing impairment impacts on children's development and potential to live productive lives. For example it reduces their speech, speech understanding and reading ability so vital for their development and academic, vocational and professional achievements. More broadly it impacts on their quality of life and human rights.
- As a consequence, the total cost for untreated hearing impairment in the EU is estimated to amount to around €224 billion per annum. This figure includes notably the medical costs, the cost for non-medical expenses such as special training and rehabilitation, and the related loss in productivity costs.
- But the picture across Europe is one of unequal and inequitable access to hearing impairment care, despite the availability of innovative medical technologies such as Cochlear implants to treat children with hearing impairment.

What needs to change?

- **At policy making level**
 - Hearing impairment must be identified as an important issue at European level– the scale of the problem and its impact on the future of children and society must be acknowledged.
 - Policy is needed that :
 - Establishes surveillance and data gathering to enable ongoing assessment of the burden of hearing impairment in children;
 - Raises awareness of hearing impairment and its impact on children and societies and promotes policy solutions to address barriers and inequities in access to hearing impairment care;
 - Acknowledges access to hearing impairment care as a right of all children that need it and fosters equal opportunities, full inclusion and active participation in society of children with hearing impairment disabilities;
 - Enables clear patient pathways to be established to detect, diagnose and treat hearing impairment at an early stage in a child's life;
 - Ensures equal and equitable access to hearing impairment care including innovative medical technologies for all children that need them;
 - Fosters best practice sharing among governments and health authorities and public private partnerships based solutions.
- **Stakeholders**
 - No one stakeholder can do it alone. All stakeholders need to work together in partnership to ensure that every child that needs it has equitable and equal access to screening, diagnosis and treatment for hearing loss.

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Introduction

The World Health Organization (WHO) estimates between 0.5 to 5 in every 1000 children worldwide are born with or develop sensorineural deafness in their early childhood²; this amounts to some 32 million children worldwide³. Approximately every year, there are 130.000 children born that have a severe sensorineural hearing loss and who are eligible for a cochlear implant. While the prevalence rate varies by country (developing countries tend to have higher rates⁴) it is a fact that children's development of speech, language, and cognitive skills, educational and career opportunities, and ultimately their quality-of-life⁵, suffer if they are denied the ability to hear. The burden of hearing loss and the need for action is increasingly recognised by the WHO⁶.



32 million children worldwide
are born with or develop
sensorineural deafness

A child with severe-to-profound bilateral hearing impairment, without cochlear implantation, may not, depending on the extent of hearing loss, be able to perceive environmental noises regardless of their loudness or nearness and he/she will certainly lack the ability to develop an understanding of human speech or develop the ability to produce speech at a level close

to that of people with normal hearing. After cochlear implantation and 6 months experience with the device, their mean pure tone average threshold might range from 20 – 44 dB HL⁷. While this constitutes a mild to moderate hearing loss, it is sufficient to hear sounds that normal-hearing people take for granted like everyday conversations, ringing telephones, traffic, and

sirens; all of which, without a cochlear implant, they would have not perceived or perceived as too soft and unclear to be of benefit (See Figure 1). Repeated studies have shown children with profound deafness who use a cochlear implant have a normal language development and are significantly better at perceiving, understanding, and producing meaningful speech and reading than they would be if they had a hearing aid or received no auditory assistance⁸. These benefits are especially pronounced if they are implanted before their first birthday⁹. Cochlear implantation should be implemented with the latest available

technology. This currently consists of highly flexible electrode arrays, that allow for structure preservation and stimulation of all frequencies through full cochlear coverage.

There are other solutions for preventing and treating hearing impairment in children, but this report will focus on one, cochlear implantation, which significantly improves the hearing abilities of the children with severe hearing loss and enhances their quality of life. In addition, cochlear implantation is the most cost effective by also creating net savings to society^{10,11}.

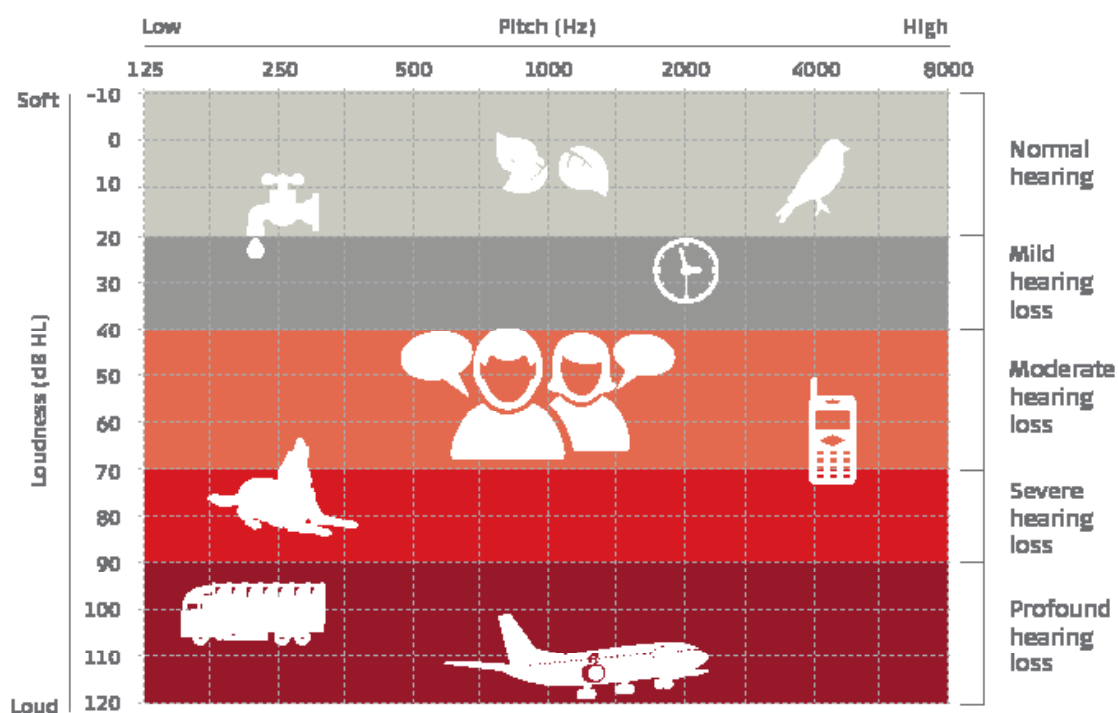


Figure 1:

An audiogram illustrating usable human hearing. Courtesy of MED-EL: <http://www.medel.com/int/audiogram/>.

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Many children will
develop the ability
to understand
conversation, without
having recourse
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Benefits of cochlear implants for children are visible in their everyday life

Listening and enjoying:

Children with cochlear implants
understand speech better and can
listen to music

In the short term, children implanted before their 1st birthday have been found to “achieve mastery of basic auditory skills” by the end of 6 months device experience¹². In the longer term, it is now realistic to expect many children who were implanted with the most modern implants when they were under 2 years old to develop the ability to understand conversation, without having recourse to lip-reading, sometimes after as little as 2-4 years of cochlear implant use, if the conversation is conducted in a quiet setting¹³. Some children can even understand conversations without lip-reading after 12 months device experience¹⁴. Even if children are implanted later, their speech perception ability improves with device experience¹⁵.

Speech understanding is not without difficulties: although children can recognize their mother’s voice and differentiate it from those of other female speakers¹⁶ they find it difficult to differentiate between speakers, especially between those of the same gender¹⁷. Further, speech understanding in noise (background noise/cocktail party effect) remains a formidable challenge¹⁸ for children with a cochlear implant – as it does for cochlear implant users of all ages – although progress is being made toward improving this¹⁹.

The benefits of auditory perception are not limited to speech understanding, like normal hearing children, many children with a cochlear implant find listening to music interesting and enjoyable²⁰. Many enjoy participating in musical activities, including playing musical instruments²¹. Children with pre-lingual deafness, never having heard music in a normal-hearing state, do not experience the same disappointment that many post-lingually deafened adults with a cochlear implant face²².

To put these challenges in their historical perspective: that prelingually profoundly deaf children could score above chance level on open-set recognition tests was not formerly regarded as a realistic goal, yet by 2002, Moog et al. found that 11 out of 17 of her subjects did, leading her to write “The progress of children with implants in the areas of speech perception, speech production, language, and reading has far exceeded the expectations of even the most optimistic.” In 2008, Gifford et al. called for new more difficult speech perception testing materials; cochlear implants users were finding the old ones just too easy.

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“The progress of children with implants in the areas of speech perception, speech production, language, and reading has far exceeded the expectations of even the most optimistic.”

Talking and being understood:

Children implanted with cochlear implant develop good speech abilities

It is now realistic to expect many children who were implanted before their 2nd birthday to develop connected speech that is easily understood by any listener within 2-5 years of cochlear implant use²³. Many children implanted later can still be expected to develop understandable speech, especially to listeners with some experience of deaf speech²⁴, after 5-10 years of cochlear implant use.

Communicating:

Today, using the telephone has become a reality for children implanted with cochlear implants

An ultimate test of speech understanding and speech production development is the ability to use a telephone. Such an achievement was unthinkable in the past; today it is a reality. Many children with a cochlear implant can use a telephone to converse about familiar topics with familiar people²⁵ and in some cases can even converse about unpredictable topics with unknown people²⁶.

Reading:

Children implanted with cochlear implants improve their reading ability

Many children with a cochlear implant attain age-appropriate or near age-appropriate reading levels²⁷. Recent studies have found that by high school age (14-18 years old) 44%-66% of cochlear implants users had reading scores at least within the age-appropriate average while a significant minority have very low reading levels²⁸. These findings, however, come from studies in which the children received their cochlear implant

after their 3rd birthday, relatively late by current practice. Little published data exists for children implanted before their 2nd birthday, however, one study of 37 children implanted at a mean 15 months old found that after a mean device experience of 4 years and 7 months, they had age-appropriate reading scores despite having an average of a 12-month delay in receptive language²⁹. As earlier implantation has been linked to greater reading development³⁰, it is entirely reasonable to expect that today's earlier implanted children will outperform the subjects of these previous studies, just as they have done in speech understanding and speech production.



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According to one study, 63% of children aged 8-10 years with a cochlear implant attended mainstream school full time. By age 15-18.5 years 75% of the same children were attending mainstream High School full-time (Geers et al. 2011).

Learning and working:

Children implanted with cochlear implants perform better at school and have better career prospects

In terms of academic and professional achievements, profoundly deaf children who receive cochlear implants, especially those who were early-implanted, substantially outperform their non-implanted deaf peers³¹. A high proportion of children with cochlear implants are educated in mainstream schools and achieve levels of education and employment that are similar to, equal to, or even higher than those of their normal-hearing peers³². In a study of 50 pre-lingually deaf children, 96% were attending mainstream schools and 64% were following the same study programme as their normal hearing peers³³. Indeed, mainstream schooling is the norm for children, regardless of their educational level, with a cochlear implant and without additional disabilities³⁴.

Age at implantation is a major predictor of subsequent educational placement and scholastic achievement. Children who are implanted before 5 years of age are more likely to enter mainstream schools than those who are implanted later³⁵. Archbold et al. (1998) found that 2 years after implantation 53% of the children who were implanted before school age were in mainstream schools compared to 6% who were already attending school before implantation.

The length of cochlear implant use is a decisive factor in full-time placement in mainstream classes: 2 years after implantation, rates of full-time placement in mainstream classrooms increased and placement in special education classrooms declined³⁶. A short duration of deafness also positively influences chances of mainstream schooling in children with a cochlear implant³⁷.

Some children who receive a cochlear implant achieve employment levels similar to their normal-hearing peers³⁸. Those who do not do nonetheless benefit: cochlear implantation opens the door to better career prospects than they would have had if they had not been implanted³⁹.

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“Many children with a CI attain age-appropriate or near age-appropriate reading levels.”

Overall, children implanted with cochlear implants and their families have better quality-of-life and psychological well-being

As the individual perceptions of quality-of-life vary, so do the outcomes of the quality-of-life studies conducted on children with a cochlear implant. Overall, the majority of children with a cochlear implant and their parents rate their quality-of-life positively. Children and adolescents with a cochlear implant are able to achieve levels of quality-of-life and psychological well-being comparable to their normal-hearing peers⁴⁰. The quality-of-life outcomes strongly correlate with the auditory perception and speech production scores⁴¹.

Children's development of: speech, language and cognitive skills; educational and career opportunities and ultimately their quality-of-life (Russel et al. 2013), suffer if they are denied auditory input.

Similar to the educational and vocational achievements, quality-of-life outcomes also show a significant inverse association with age at implantation and a significant positive association with the duration of cochlear implant use⁴². Early implantation improves disease-specific health-related quality-of-life covering the domains of basic sound perception, advanced sound perception, speech production, self-esteem, activity, and social interaction⁴¹.



Early implantation improves profoundly deaf children's quality-of-life, educational achievements, increases their future earning power, and enhances their communication abilities.

In particular, cochlear implant users and/or their parents report a high level of satisfaction with life, well-being, and self-confidence, and a positive self-image and strong social skills⁴³. Furthermore, cochlear implant use seems to reduce psychological symptoms caused by hearing loss, such as anxiety, perceived stress, and depression⁴⁴.

Cochlear implantation not only supports the general-functioning and quality-of-life of children with hearing loss, it enhances their family's quality-of-life⁴⁵.

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Future potential: Early implantation and widespread hearing screening will bring more benefits for hearing impaired children and society

Due to the advent and widespread adoption of universal newborn hearing screening in Europe, in contradiction to the global situation⁴⁶, which enables congenital deafness to be detected (and therefore subject to intervention) very soon after birth, and continually improving cochlear implant technology, it is entirely reasonable to expect that

a greater percentage of children being implanted today, with ever-improving technologies and surgical techniques, will develop greater audiological abilities, attain higher professional levels, and enjoy a greater health-related quality-of-life than those hitherto studied.

Summary

- Children with cochlear implants achieve higher levels of speech understanding, speech production, reading, educational advancement, professional status, and quality-of-life than do profoundly deaf children without cochlear implants or hearing aids.
- Earlier implantation, before 12 months of age, has been linked with increased benefit. While there is considerable variation in scores – some children develop skills very quickly, other barely or not at all – children should participate in habilitation sessions and parents must interact orally and regularly with the child to maximize potential benefit.
- Cochlear implantation is the most cost effective solution by also creating net savings to society over a patient's life-span such as reduced educational costs or expanded earning opportunities.

Despite the benefits to the child and society of cochlear implantation, its potential remains unrealised in the European Union. The picture in the European Union is one of inequities and inequalities.

Barriers to paediatric hearing implants in the European Union

A patchwork framework: The EU, member states, and health care competencies

National variations in access to hearing implants: Cochlear implantation is the most beneficial intervention for the vast majority of children with severe and profound deafness and, as such, is available to resident children in European Union member states like France, Germany, the Netherlands, and the UK. Children resident in other member states, however, may face significant financial obstacles to obtaining a cochlear implant and subsequent rehabilitation.

The coverage of a single cochlear implant for children and adults with bilateral hearing loss is guaranteed in almost all EU member states. The rules regarding bilateral implants, on the other hand, are widely divergent: Germany, Austria, Norway, and some regions in Italy cover implants for young and old alike. In some member states, only children who fulfil certain indications may receive a second implant, and adults are not entitled to a second implant. In Belgium, for example, bilateral cochlear implantation is available only to children. In other member states, bilateral implantation is available only to children under a certain age or not at all.

EU efforts are encouraging but need to go further: Individual member states are responsible for: financing their health care system; designing the infrastructure of their health care system; providing health care to their residents; defining benefit entitlements; assessing their health care technology and, formulating and implementing reimbursement policies. In stark contrast, the EU's health-related competency is restricted to public health issues (Art 168 Treaty of the Functioning of the European Union), although efforts are currently being made to restructure national health policies and enhance health care coordination among member states. While such coordination is encouraging, the wide variety of national arrangements for financing or reimbursing residents for receiving cochlear implants and related services (e.g. screening, diagnosis, rehabilitation, the provision of batteries) – especially in cross-border healthcare – is unlikely to change in the near future, according to individual member states' financial means and priorities.



An important factor contributing to this unequal situation is the division of health care related competencies between national governments and the EU.

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Article 35 of the Charter of Fundamental Rights of the European Union

HEALTH CARE

Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices. A high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities.

The right to health

A European right: Article 35 of the Charter of Fundamental Rights of the European Union states that “everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices.”

The EU is also a member to the United Nations’ Convention on the Rights of Persons with Disabilities – the first time that the EU has acceded to an international human rights treaty as a legal entity. Importantly, the Convention enshrines all human rights, including the right to health (Article 25), in an inclusive and accessible frame. It underscores that most persons with disabilities are per se healthy but suffer from their needs being overlooked or not taken seriously and therefore face many obstacles in accessing health care on an equal basis with others.

A right recognised at international level: Health is a fundamental human right that is indispensable for the exercise of other human rights as contained in the UN International Bill of Rights, which includes the rights to food, housing, work, education, human dignity, life, non-discrimination, equality, the prohibition against torture, the right to privacy, access to information, and to the freedom of association, assembly, and movement. These and other rights and freedoms address integral components of the right to health.

Indeed, the right to health is internationally recognised in the Universal Declaration of Human Rights (Article 25), the Convention on the Elimination of All Forms of Racial Discrimination (Article 5), the Convention on the Elimination of All Forms of Discrimination Against Women (Articles 11 & 12), the Covenant on Economic, Social & Cultural Rights (Article 12), and the Convention on the Rights of the Child (Article 24).

The Right to Health is internationally recognised in the following sources:

Universal Declaration of Human Rights (Article 25)

Convention on the Rights of Persons with Disabilities (Art 25)

Convention on the Elimination of All Forms of Racial Discrimination (Article 5)

Convention on the Elimination of All Forms of Discrimination Against Women (Articles 11 & 12)

Covenant on Economic, Social & Cultural Rights (Article 12)

Convention on the Rights of the Child (Article 24)

Non-discrimination and the right to health

Like all human rights, the right to health calls for equal treatment and non-discrimination: everyone shall have equal access to health care services and standards without differential or discriminatory treatment due to gender, age, socio-economic status, or disability.

Despite these enshrined rights, people with hearing disability still face discrimination: persons with disabilities face myriad obstacles in accessing health care, not least of which are attitudinal barriers. A report by the EU Agency for Fundamental Rights highlights the impact of medical staff being largely unaware of how bias and prejudice can have profound effects on the quality of health care across different groups⁴⁷. Frequently, persons with disabilities endure the consequences of stigma and prejudice related to their impairment; persons with severe or profound hearing loss are particularly likely to face such social barriers.

Accessibility and the right to health

Hearing disabilities are not set on an equal footing with other disabilities: Ramps, lifts/elevators, and other aids for persons with mobility disabilities are readily available in member states; however, aids for persons with communication disabilities, particularly hearing loss, often remain absent. Until greater efforts are made to provide persons with communication disabilities with alternative communication formats or media that are easy-to-read and use, they will continue to suffer from an impingement of their right to equal access.

People with hearing deficiencies still face financial barriers and socio-economic disadvantages: Economic accessibility is a major factor in ensuring the human right to health care. "Affordability" connotes all measures aimed at ensuring that persons who are socio-economically disadvantaged receive support in attaining their rights. Financial barriers for persons with disabilities are compounded by disadvantages in education and employment and consequently, an overall higher prevalence of poverty.

Removing Barriers to Hearing Health Care

Ending national variations in access to cochlear implantation: An individual's right to benefit from medical treatment throughout the EU is limited by the conditions established under the national laws and practices of the member state in which he/she is a legal resident. For example, if a child lives in a member state in which bilateral cochlear implantation is included in the benefit package of the country's health care system, that child has access to an advanced medical technology on the basis of the EU Charter on Fundamental Rights.

Cross-border treatment and the right to health

Cross-border healthcare is a right in the EU: The recently implemented Directive 2011/24/EU on cross-border health care clarifies EU residents' right to access and be reimbursed for receiving safe and good quality treatment within EU member states. EU residents who receive medical care in another EU member state enjoy identical rights of access and quality of care as do the residents of that member state. If an EU resident is entitled to a particular treatment in their home country, they are - under certain circumstances - entitled to access the same treatment in any other EU member state and be reimbursed for that treatment by their home country.

This Directive will benefit the health systems of EU member states by improving international cooperation on: eHealth tools; the use of health technology assessment; and the pooling of rare expertise. This is a first step closer towards equal access to health care and an "informed patient" with more than one opportunity.

If, however, a child lives in a member state in which bilateral cochlear implantation is not included in the benefit package of the country's health care system, then he/she is denied "equal footing" with other EU residents; due solely to the reimbursement regulations in his/her member state. Further, although a unilaterally implanted child may receive a second implant in any member state, such "planned" treatment typically requires prior authorization by his/her family's insurer. Generally, insurers will assume responsibility for the costs of a procedure only if it is an entitlement in the member state in which an individual has health care coverage.

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The need for a EU-wide solution to end discrimination and inequalities in access to hearing implantation: This discrepancy between the EU's human rights commitments and the provision of equitable health care services in general and hearing implants in particular, calls for an EU-wide solution which would conform to the basic principles of the European Treaty. This could take the form of a minimum level of benefits in all member states that is based on EU human rights policy and should be included in the EU's non-discrimination and human rights policy. Under

such a policy, children with profound deafness would still have to obtain prior authorisation in accordance with national rules (e.g. regarding medical necessity and cost-effectiveness) before cochlear implant surgery, but these national rules would be derived from human rights policies at EU-level. This would uphold the objectives of European human rights obligations and be a step towards ensuring that all persons benefit from an equal access to health care and health technology.

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“Alone we can do
so little; together
we can do so much”

Helen Keller

A final word

Hearing: it is a basic sense and hearing loss health care is a fundamental right for all children. Yet as this paper discusses there are today many children in Europe and across the world that continue to be impacted by hearing loss. Indeed there are challenges to overcome to ensure that all children who need it have equitable and equal access to hearing loss care, but solutions can be found. By ensuring the right policies are put in place to reduce inequalities and

inequities, the barriers to hearing loss care can be broken down and potential of innovative medical technologies such as cochlear implantation can be realized.

Let's all work together to make this happen and enable all children with hearing impairment the opportunity to listen and enjoy music and sound, talk and be understood, communicate by telephone or other means, read, learn, work and ultimately have better lives!



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