















# **Manifesto on Hearing Loss and Disability**

#### Overview

In Europe, 10% of the total population (52 million people) self-reports to experiencing hearing loss, 73% consult a medical professional, but only 50% are referred to hearing care professionals. Hearing loss is a huge problem for the health of Europe's citizens, threatening to put huge pressure on Europe's health and social care systems if left untreated. Innovative medical technology, such as hearing aids and hearing implants, can alleviate the burden. Action from European policy-makers is called to help raise awareness of this condition, look at effective ways of prevention, facilitate access to these technologies where appropriate, improve care and share best practices amongst Member States.

# The European Coalition on Hearing Loss and Disability calls upon:

### The Member States:

- 1. **To share best practice on hearing care**, including preventative measures and early screening programmes to identify and diagnose hearing loss;
- 2. **To integrate strategies for hearing care into primary health care systems** which effectively address prevention and early identification;
- 3. **To promote access to hearing devices** which includes cochlear implants, hearing aids and other assistive devices;
- 4. To remove age limits in disability support measures that prevent older persons with disabilities, such as hearing impairment, from enjoying their rights under the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The CRPD applies equally to all persons with disabilities regardless of their age. The lack of support to access hearing devices and similar aids means that older persons cannot afford to equip themselves, becoming increasingly isolated from their social environment, with all the negative impacts this has on their health and wellbeing;
- 5. **To promote effective initiatives to improve access to information** for persons with disabilities with respect to public facilities, public buildings and audio-visual media services;<sup>2</sup>
- 6. To ensure education and recognition for hearing care professionals in their country.

#### The European Commission and the Council:

- 1. To take the lead in ensuring that access to professional hearing care is a right, including diagnosis, rehabilitation, service and maintenance;
- 2. To support Member States to coordinate health policies and promote healthy ageing;
- 3. **To develop a European strategy on hearing loss** focusing on equality, prevention and rehabilitation to make everyday life easier for hard of hearing people and ensure that this strategy is led by experts working in the field;
- 4. **To launch programmes to increase awareness** of hearing loss as a cause of social isolation, depression and deterioration of both mental and physical health for older people and, therefore, of the importance of hearing loss geriatric care;
- 5. **To invest in research on hearing loss**, its prevention and rehabilitation, and to share relevant studies and statistics.

<sup>&</sup>lt;sup>1</sup> AEA, EFHOH & EHIMA, *Getting our numbers right on Hearing Loss Hearing Care and Hearing Aid Use in Europe*, July 2017. Available at: <a href="https://www.aea-audio.org/portal/index.php/aea-action-plan/awareness">https://www.aea-audio.org/portal/index.php/aea-action-plan/awareness</a>

<sup>&</sup>lt;sup>2</sup> This includes interpreters and subtitles both on TV and cinemas as well as the full implementation of the Audio-Visual Media Services Directive9 (2010/13/EU).

















# **Explanatory notes:**

# a) Hearing loss has huge costs to the economy

Globally, the annual cost of hearing loss to the economy is equivalent to the GDP of the Netherlands.<sup>3</sup> The World Health Organization (WHO) estimates that in Europe the total cost of untreated hearing impairment amounts to a startling €178 billion each year.<sup>4</sup> These costs are due to health system expenditure, loss of productivity caused by unemployment and premature retirement, societal costs - social isolation, communication difficulties and stigma - and costs of additional educational support for children with hearing loss aged 5-14.<sup>5</sup>

# b) Hearing loss reduces a person's chances of employment

Adults with unaddressed hearing loss have a higher unemployment rate than the rest of the population.<sup>6</sup> Further impact includes increased levels of sick leave and limited opportunities for career progression, ultimately leading to job loss. The impact of unemployment or premature retirement on the economy is equated to a major likelihood to need state benefits.<sup>7</sup> Preventing and treating hearing loss increases a person's chance of employment and their earning potential. Research shows that, at the time of initial cochlear implantation, 60% of patients were unemployed; however, the unemployment rate was reduced to 49% following the cochlear implantation.<sup>8</sup>

# c) Hearing loss reduces a child's right to equal education opportunities

Children's development of speech, language, and cognitive skills, along with educational and career opportunities and ultimately their quality of life, can remarkably be damaged if children are denied the ability to hear. The World Health Organization estimates that between 0.5 and 5 in every 1000 children worldwide are born with or develop sensorineural deafness in their early childhood; this amounts to some 32 million children worldwide. According to WHO's assessment, 60% of hearing loss in children can be prevented. 10

Profoundly deaf children who receive cochlear implants, especially those who are early-implanted, substantially outperform their non-implanted deaf peers. Around 63% of children aged 8-10 years with a cochlear implant attended mainstream fulltime education. The ability to learn on a similar level as their peers is demonstrated by statistics that reveal that early implantation allows 44%-66% of children to reach and maintain age-appropriate reading scores by 14-18 years of age.<sup>11</sup>

# d) Hearing loss has an overall impact on general health

Untreated hearing loss puts pressure on Europe's already struggling health and social care systems, partly because it risks the onset of other diseases. Hearing loss is associated with a range of comorbidities:

<sup>&</sup>lt;sup>3</sup> The World Health Organisation, *Action for Hearing Loss, Make a Sound Investment*, 2017. Available at: <a href="http://www.who.int/pbd/deafness/world-hearing-day/WHD2017Brochure.pdf?ua=1">http://www.who.int/pbd/deafness/world-hearing-day/WHD2017Brochure.pdf?ua=1</a>

<sup>&</sup>lt;sup>4</sup> Best L, Laureyns M, Hougaard S, *Make a sound investment: Prevent and treat hearing loss*, 3 March 2017. Available at: <a href="https://www.euractiv.com/section/health-consumers/opinion/make-a-sound-investment-prevent-and-treat-hearing-loss/">https://www.euractiv.com/section/health-consumers/opinion/make-a-sound-investment-prevent-and-treat-hearing-loss/</a>

<sup>&</sup>lt;sup>5</sup> The World Health Organisation, loc. cit.

<sup>&</sup>lt;sup>6</sup> The World Health Organisation, Report by the Secretariat on Prevention of deafness and hearing loss, 4 May 2017.

<sup>&</sup>lt;sup>7</sup> For example, in the UK, 41% who retired early did so directly because of untreated hearing loss. Source: Arrowsmith L, Hidden Disadvantage, Why people with hearing loss are still losing out at work, Action on Hearing Loss Report 2013. p. 37 <a href="https://www.actiononhearingloss.org.uk/~/media/Documents/Policy%20research%20and%20influencing/Research/Hidden%20Disadvantage/Hidden Disadvantage full report.ashx">https://www.actiononhearingloss.org.uk/~/media/Documents/Policy%20research%20and%20influencing/Research/Hidden%20Disadvantage/Hidden Disadvantage full report.ashx</a>

<sup>&</sup>lt;sup>8</sup> Lavis JN, Posada FB, Haines A, Osei E. Bending the Spend: Expanding access to hearing technology to improve health, wellbeing and save public money, The Lancet 2004;364:10.

<sup>&</sup>lt;sup>9</sup> The World Health Organisation, WHO Fact sheet February 2014. Available at: <a href="http://www.who.int/mediacentre/factsheets/fs300/en/">http://www.who.int/mediacentre/factsheets/fs300/en/</a>

<sup>&</sup>lt;sup>10</sup> The World Health Organisation, Report by the Secretariat on Prevention of deafness and hearing loss, 4 May 2017

<sup>&</sup>lt;sup>11</sup> Geers AE & Hayes H, Reading, writing, and phonological processing skills of adolescents with 10 or more years of cochlear implant Experience, 2011 Ear Hear 32(1 Suppl):49S-59S.

















- Cognitive decline people with mild hearing loss have nearly twice the chance of developing dementia as people without any hearing loss.<sup>12</sup>
- Depression linked to social interaction and lack of participation in society. The Institute of Deafness and Other Communication Disorders revealed that more than 11% of those with hearing loss also had depression, compared to 5% in the general population.<sup>13</sup>
- Dependence untreated hearing loss increases the chance of being dependent on others by 33%, while the use of hearing aids and cochlear implants for these subjects significantly reduces this risk.<sup>14</sup>
- Frequent falls and increased risk of accidents among pedestrians.

# e) As Europe's population ages, so will the burden of hearing loss

Public spending on ageing in the EU accounts for 50% of general government expenditure.<sup>16</sup> The number of Europeans over 65 will double in the next 50 years, and the number of over 80's will almost triple.<sup>17</sup> The inevitable act of ageing is the most common cause of hearing loss in adults. In Germany, for example, 1% of 14 to 19 years old experience hearing loss, and that statistic rises to 54% for those over 70 years old.<sup>18</sup>

There are huge social and economic consequences of age related hearing loss. It can restrict a person's independence and make it more difficult for older people to take care of themselves. This means that they are more likely to depend on friends and family for support and can accelerate their progression into facilitated living or social care. The lack of independence can also be incredibly isolating for the older population, preventing their participation in social activities and leading to isolation and depression. The lack of independence might also impact their ability to contribute to the silver economy.<sup>19</sup>

## f) Need to improve access to hearing aids, cochlear implants and other hearing technologies

Hearing loss can be addressed through provision of national screening programs and easier access to interventions, including cochlear implants and hearing aids. WHO recognises the need to develop and monitor screening programmes for early identification of ear diseases, targeting infants, young children, adults (starting at the age of 50<sup>20</sup>) and people exposed to noise in occupational and recreational settings.<sup>21</sup> Hearing technologies can dramatically improve the ability to hear and therefore reduce negatives consequences on the social, mental and physical wellbeing and health of individuals with hearing loss.

<sup>&</sup>lt;sup>12</sup> Amieva H, Ouvrard C, Giulioli C, et al. *Self-reported hearing loss, hearing aids, and cognitive decline in elderly adults: A 25-year study.* Journal of the American Geriatric Society, 2015, 63(10):2099 – 104.

<sup>&</sup>lt;sup>13</sup> Chuan-Ming Li, Xinzhi Zhang, Howard J. Hoffman, et al, *Hearing Impairment Associated With Depression in US Adults, National Health and Nutrition Examination Survey 2005-2010*, JAMA Otolaryngol Head Neck Surg, April 2014, 140(4):293-302 <a href="http://jamanetwork.com/journals/jamaotolaryngology/fullarticle/1835392">http://jamanetwork.com/journals/jamaotolaryngology/fullarticle/1835392</a>

<sup>&</sup>lt;sup>14</sup> Étude PAQUID/Amieva: *La réhabilitation auditive au secours du vieillissement*, March 2017. Available at: <a href="https://www.edp-audio.fr/actualites/recherche/5250-etude-paquid-amieva-la-rehabilitation-auditive-au-secours-du-vieillissement">https://www.edp-audio.fr/actualites/recherche/5250-etude-paquid-amieva-la-rehabilitation-auditive-au-secours-du-vieillissement</a>

<sup>15</sup> Jiam NT, Li C & Agrawal Y. Hearing loss and falls: A systematic review and meta-analysis. Laryngoscope. 2016 Nov;126(11):2587-2596.

<sup>&</sup>lt;sup>16</sup> European Commission, *Growing the European Silver Economy, Background paper, 25 February 2015.* Available at:

http://ec.europa.eu/research/innovation-union/index en.cfm?section=active-healthyageing&pg=silvereconomy

<sup>&</sup>lt;sup>17</sup> European Commission, European Innovation Partnership on Active and Healthy Ageing. Available at: https://ec.europa.eu/eip/ageing/about-the-partnership\_en\_

<sup>&</sup>lt;sup>18</sup> D'Haese P, How can innovative technologies improve the quality of life for people suffering from hearing loss?, 2016 p. 37 <a href="http://www.lse.ac.uk/LSEHealthAndSocialCare/pdf/eurohealth/EHv22n3-WEB-onlineversion-310816.pdf">http://www.lse.ac.uk/LSEHealthAndSocialCare/pdf/eurohealth/EHv22n3-WEB-onlineversion-310816.pdf</a>

 <sup>19</sup> D'Haese P, *loc. cit*.
20 Hearing loss is the most significant modifiable risk factor for dementia. Studies underline the importance to act at *midlife* (age 45–65 years) which means that screening for hearing loss and intervention with hearing aids should start the latest at 50 years of age. Source: The Lancet Commissions, *Dementia prevention, intervention, and care*, 20 July 2017. Available at: <a href="https://www.thelancet.com">www.thelancet.com</a>

<sup>&</sup>lt;sup>21</sup> The World Health Organisation, *Resolution on Prevention of deafness and hearing loss*, 31 May 2017. Available at: <a href="http://apps.who.int/gb/ebwha/pdf">http://apps.who.int/gb/ebwha/pdf</a> files/WHA70/A70 R13-en.pdf?ua=1

















Hearing devices are covered at least partly by the national health care insurance in most European countries, but there are large disparities. Access to hearing care and hearing devices is much poorer in countries that provide little or no reimbursement.<sup>22</sup> Cochlear implants, used to treat those who experience hearing loss too severe to benefit from a hearing aid, are largely funded by Europe's national health care systems. However, more work needs to be done to ensure patient access. In the United Kingdom, for example, it is estimated that only one in twenty people who could benefit from a cochlear implant has access to such technologies.<sup>23</sup> WHO acknowledges the importance of technologies and assistive devices. The United Nations' Agency recently urged Member States to improve access to affordable and high quality hearing devices as part of their universal health coverage.<sup>24</sup>

<sup>&</sup>lt;sup>22</sup> AEA, EFHOH & EHIMA, *Getting our numbers right on Hearing Loss Hearing Care and Hearing Aid Use in Europe*, July 2017. Available at: <a href="https://www.aea-audio.org/portal/index.php/aea-action-plan/awareness">https://www.aea-audio.org/portal/index.php/aea-action-plan/awareness</a>

<sup>&</sup>lt;sup>23</sup> Action on Hearing Loss, Hearing screening for life. Available at: <a href="https://www.actiononhearingloss.org.uk/get-involved/campaign/hearing-screening-for-life.aspx">https://www.actiononhearingloss.org.uk/get-involved/campaign/hearing-screening-for-life.aspx</a>

<sup>&</sup>lt;sup>24</sup> WHO, Resolution on Prevention of deafness and hearing loss, 31 May 2017

















# The European Coalition on Hearing Loss and Disability: Founding Members:

Health First Europe (HFE) is a non-profit European organisation bringing together patients, doctors, nurses, hospitals, academics, experts and industry who work to ensure that patient access to modern, innovative and reliable medical innovation and healthcare is regarded as a vital investment in the future of Europe. HFE calls for truly patient-centred healthcare, a system where all European citizens could benefit from the best medical treatments available. There are currently 23-member organisations of HFE and 29 MEP Supporters.



The European Federation of Hard of Hearing People (EFHOH) is a non-profit European non-governmental organisation consisting of/for hard of hearing, late deafened people, those living with tinnitus, hyperacusis, Ménière's disease and Cochlear Implants, as well as parent organisations and professional organisations. EFHOH's aim is a Europe where hard of hearing people can live without barriers, and have the opportunity to participate at all levels in society. EFHOH membership currently represents 21 different countries and over 52 million hard of hearing people across the EU.



The European Association of Hearing Aid Professionals (AEA) was founded in 1970 as the European umbrella organisation for "Hearing Aid Professionals". It is an association of national professional organisations representing a total of 20,000 hearing care professionals in 13 countries: Austria, Belgium, France, Germany, Greece, Italy, the Netherlands, Romania, Poland, Portugal, Spain, Switzerland and the UK. AEA strives to improve the quality of hearing care services, ensure a transparent, fair and competitive market, and safeguard freedom of choice in the interest of the end-user.



AGE Platform Europe is a European network of non-profit organisations of and for people aged 50+, which aims to voice and promote the interests of the 190 million citizens aged 50+ in the European Union and to raise awareness of the issues that concern them most. Its work focuses on a wide range of policy areas that impact older and retired people. These include issues of anti-discrimination, employment of older workers and active ageing, social protection, pension reforms, social inclusion, health, elder abuse, intergenerational solidarity, research, accessibility of public transport and of the build environment, and new technologies (ICT).



**EURO-CIU** is a non-governmental and non-profit association, which was founded in Luxembourg in 1995; it consists of 31 member associations from 23 European countries representing almost 150.000 cochlear implant (CI) users across Europe. EURO-CIU Mission consist in promote, advance and protect the rights of cochlear implant users —both adults and children — in Europe, working for equality of access for cochlear implantation in all countries, accessibility for all — breaking all communication barriers — as well as inclusion for CI users in society and rehabilitation and appropriate training for both CI's adults and CI's children users.



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The European Hearing Instrument Manufacturers Association (EHIMA) was founded in 1985 and represents European hearing instrument manufacturers, producing up to 90% of hearing aids made in Europe. EHIMA believes in the right of every hearing-impaired person to hear well and, therefore, supports the UN Declaration on the Rights of Persons with Disabilities. The organisation also EHIMA supports the introduction of hearing screening programs both for newborns, children and adults, to ensure early intervention and optimum cognitive capacities.



**The Ear Foundation** is an independent charity that helps deaf people and their families make the best use of technology to improve hearing, communication and spoken language. Having brought cochlear implants for children to the UK in 1989, the organization aims to bridge the gap between the clinics where these exciting technologies are fitted and the local community where they are used in everyday life. The Foundation provides family and education programme.



The International Federation of ORL Societies (IFOS) is a non-political organization representing over 50,000 otolaryngologists belonging to about 120 member nations. IFOS was founded in 1965 to provide continuity between World Congresses, it has evolved to deal on a global basis with the problems of people with ORL disease by means of an active secretariat and committee structure, lobbying the World Health Organization and providing interchange between centers, especially in Europe through the Twin Cities Project.

