

Interview: **Leo De Raeve, founder of ONICI**

"As counsellors, we have to open up to the Deaf Community, but the reverse is true as well."

Leader

Last year marked the tenth anniversary of the ONafhankelijk Informatiecentrum over Cochleaire Implantatie (ONICI / Independent Information Centre for Cochlear Implantation). In honour of this occasion, a conference was held in Antwerp on 20 and 21 November called "International State of the Art Meeting on (Re)habilitation of Children and Adults Receiving Cochlear Implants". It is about time to ask the founder of ONICI, Leo De Raeve, about the purpose of ONICI and the changes over the past ten years.

10 years ago, it was not easy to find up-to-date information in Dutch about CI on the internet. Information that was available was often incorrect, available in other languages or biased information such as advertisements. According to De Raeve, there was a need for good information provision: "ONICI was founded for the purpose of making information available in Dutch online about the different CI brands and the results of scientific research so that this information can be accessed by users, professionals and parents of deaf children". But, ONICI has been expanding its work considerably. For instance, every six months, a newsletter is sent to over 1300 interested parties and study days and workshops are organised in Flanders and the Netherlands. Finally, ONICI also focuses on translating and making suitable rehabilitation material available.

Multi-disciplinary Counselling

In recent years, ONICI has focused on providing information regarding rehabilitation and counselling. De Raeve indicates that it is not easy for parents of deaf children to make the right choices with respect to counselling: "If there's a whole range of possibilities from a purely visual approach to a purely auditory aural approach, then I'm in favour of taking the positive aspects of both approaches. I feel it's going too far to say that a purely aural approach is the best. This'll be the right approach for some children, but for just as many deaf children it won't be." According to De Raeve, you have to make choices and you do so based on good follow-up and scientific knowledge. "This isn't

always easy, because few decent scientific studies in the field of education and rehabilitation are available."

There still is a large variation in the results CI children display. "It's hard to easily predict how a one-year old will be developing at age 5. If a deaf child is discovered in a family, the family needs to be informed well step-by-step, the child needs to be monitored well and only then can we ascertain what the best time to turn to CI is." A continuous multi-disciplinary approach cannot be assumed. De Raeve says: "We know that we can achieve very good results if the wheels in motion are connected well. That means that if the doctor has inserted the implant properly, if the CI is set up well, if the parents deal with it well, if the parents check the functioning of the CI well, if the child's and family's counselling is good, if the child has no additional needs, if habilitation, counselling and professional support has a good quality, etc. But if there's a gap, then it doesn't fit anymore and we need to adjust (as soon as possible)".

Technical Developments

In recent years, technology has developed at a rapid pace. De Raeve: "However, there's still quite a large gap between surgery and technology on the one hand and counselling on the other; I feel we can't keep up with the technology. We're insufficiently aware of what the technology is or would be capable of. Thanks to neuroscience, we got to know more and more for example about the plasticity of the brain, but we're unable to create a relationship between that knowledge and practice. There's a large gap between research and practice." According to De Raeve, this gap is larger in education than in early counselling: "People counselling the littlest ones usually went along with the changes, but when I see the way in which some people work in education, I feel that they're running behind on current developments."

Dialogue with the Deaf Community

Leo De Raeve identifies the fact that, like in the Netherlands, Belgium too has a difference of opinion with respect to education and counselling children with a CI. "I have the feeling that the older deaf people are more easy-going with respect to CI and the use of spoken language by deaf children than some of the younger deaf people. Johan Weseman is an example. A wonderful man who has stood up for the Deaf Community for years and who has achieved a lot. He is very open-minded, which I feel is what is lacking in some of the young deaf people in the Netherlands and Belgium. I think they're fighting so hard for their cause because they see that what they're fighting for is being increasingly pushed aside. As a reaction, you start fighting more to put forward your point of view and ideas".

That is why De Raeve is in favour of dialogue. "I feel that, as counsellors, we need to open up to the Deaf Community, but they need to do the same. The Deaf Community needs to open up to all those young children of today! Their need to meet each other now, as youths and as adults, remains. The Deaf Community will have to be open to the fact that some deaf people will communicate in spoken language (whether supported by signs or not) and not in sign language. Why shouldn't that be possible?"

Culture is something dynamic that can change over time. If you try to stop these changes, many deaf young people will not feel at home in that Deaf culture, which would be a shame, because literature and daily practise shows very strongly that deaf and hard of hearing young people and adults still have the need to get together and exchange ideas.

Marjan Bruins and Bernadette Vermeij, editors Van Horen Zeggen

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<http://www.simea.nl/vhz/>

ONICI website: www.onici.be


