From:

To: <u>Community Affairs, Committee (SEN)</u>

Subject: Let Us Hear Additional Submission to Senate Inquiry inti the NDIS Bill

Date: Wednesday, 27 February 2013 11:09:39 PM

Please Consider this email as a formal Submission to the Senate Standing Committee on Community Affairs Inquiry into the National Disability Insurance Scheme Bill 2012. It is in addition to our first Submission.

Let Us Hear is an organisation set up in 1997 to request the Federal Government Office of Hearing Services to allow previous child clients of Australian Hearing (AH) to continue to access its Services over the age of 21years which was the age these Services ceased at that time. Since then, the present Federal Government has extended the age of cessation to 26 years. (May Budget 2011) Let Us Hear has continued to campaign for all previous child clients of A H to have the option of continuing to stay with A H if they so desire as they have had trusted expert dedicated professionals all their childhood there and they ,as mostly congenital and early onset deaf and hearing impaired people, wish to continue with this support. Most of the members of Let Us Hear are oral deaf and hearing-impaired people and so have been taught to rely on listening with their hearing devices (hearing aids and Cochlear Implants) some also using lipreading to communicate. To lose the great benefit of their listening device is a tragedy. AH services allow Cochlear Implantees free batteries, cords ,processor updates and repairs up to 26 years. The original costs of the operations are not included in AH services.

Our experience is that a large number of our group cannot afford the cost of new hearing aids available in the hearing aid Industry which could be anything from \$3000-\$4000 onwards. These deaf and hearing impaired people are extremely dependant on and possessive of their hearing devices as these help them keep in communication with their families, their workplace and their whole community. It was brought to our attention in early 2011 by the Employment Agency of the NSW Deaf Society that there were some very depressed people who couldn't afford new devices and some had even committed suicide so keen are they on being included in everyday life by oral communication. Another result is that without being able to monitor their own voices with these devices, their speech quality gets much more unintelligible which quantifies their isolation.

Let Us Hear would like the NDIS to agree to this group of oral deaf and hearing-impaired people to have the option of continued access after the cut-off age of 26 years to Australian Hearing Services through discussion with the Federal Government. This would mean an agreed payment through the Legislation but this would appear to be a much more satisfactory arrangement for them than the often very "hit-and-miss" set-up now with the outside Industry which is a commission-based one. We feel it should be a licensed one.

At present the only deaf and hearing-impaired people who can continue to have access to Australian Hearing over the age of 26 are the Disability Services Pension (DSP) people who use hearing aids.

The situation of Cochlear Implantees who are on the DSP is not the same over the age of 26 years as the hearing aid wearers. Those complex cases are given free access to AH at the discretion of the Minister .As I believe it at the present time, the veterans are given free cochlear services but not the DSP deaf or Deaf/Blind people who are still given batteries and cords but not updated processors. As these cost \$12,000, these are out of the reach of most DSP people. This would be a very important matter for NDIS to cover.

There are certain aspects of cochlear implant usage which are becoming apparent. The implant itself is at a certain level technologically and the first processor matches this. These processors can be repaired by cochlear. The "shelf-life" is about 3 years. Those with private health

insurance can obtain cochlear services free. After some upgrades of the processor, there seems to occur a mismatch of technologies as the upgrade has moved ahead of the implant. There then is created a situation whereby the implantee has a choice. He/she could access the new upgrade by way of a new operation for a new implant or stay with the last processor as long as Cochlear will continue to make the parts to repair the old processor. However in 2011, Cochlear contacted the Deaf/Blind Association saying they will not be making the parts for the old processors any more so several of those implantees could not use their Cochlear Implants any more as they can't afford new operations. Also deaf implantees on the DSP likewise cannot afford new operations.

It would appear to be a good idea for Cochlear to discuss these matters with their clients before initial operations.

Let Us Hear supports the setting up of the NDIS and also supports the individually based concept. This gives the disabled people more control of their lives and to realise their potential more readily and should be eligible for the NDIS.

Let Us Hear wants to say that hearing loss is a communication disability and any personnel working within the NDIS must be able to comprehend what is required always. Deaf people fall into 3 different groups...the oral deaf which Let Us Hear represents, the signing deaf and the acquired deaf who are generally deaf after becoming adults and therefore grew up in a hearing environment.

- 1.1If the person is not eligible for NDIS, how can deaf people know that they can be referred to other systems? The NDIS will need to have made a very full information booklet to give those who are not eligible. Some deaf people may be very dissatisfied by being refused eligibility for NDIS as deafness can appear at any age.
- 1.2 If the Agency funds community-based supports for the disabled, they must make sure that these will be of true benefit to the deaf person's future in all ways not just for a short period. This will need a proper inquiry into the substance of the support .As far as the deaf are concerned, it is very advantageous for them to be included in all sorts of community occasions as deafness is a very isolating disability and inclusion in these would be a great support.
- 2.1The Rules need to say exactly what kind of information the Agency needs to make sure that people know what is required to be eligible as far as age is concerned especially as deafness is a disability very common in old age. Also the age requirements in the Trials for South Australia and Tasmania need to be well advertised.
- 2.2They need to know that that they need to be Australian residents and how long one needs to live in a certain area to join in the Trial .
- 2.3 If the person was getting some sort of support before, the Rules need to say something to clarify what will happen to those supports after NDIS starts and how they will compare with each other.
- 2.4 The Rules need to say something about if the person's disability is permanent and makes a severe impact on their lives, deaf people need to know what the Agency will look for. Will they need to provide audiograms for example? Also the type of people making these assessments especially based on what a person would like to do or can do, not just diagnosis
- 2.5 The Agency will need to look at the quality of early intervention in order to give the person as advantageous a future as possible. There will need to be well-qualified people in the Agency who can ascertain these matters. Eg: there needs to be people who are knowledgeable about and share the militancy of the signing Deaf and their Culture who possibly would not be qualified in the aspirations and directions of the oral deaf.

The Agency must be very careful if it may suggest a better type of Early Intervention program so

that all interested parties end up in agreement. As far as deafness is concerned, there are very different types of early intervention programs offered. Some deaf people are looked after by Australian Hearing for hearing devices or special schools are available for Auditory Verbal Programs. Some are associated with Cochlear Implant Programs . Some are involved with early signing programs. It depends on the philosophy of the parents and the program.

3.1 The deaf and hearing-impaired need to understand that the NDIS requires a "support plan" brought in by each applicant which will include two statements namely :a) the goals, aspirations and living circumstances and b) the supports that need to be provided or funded for them by NDIS as well as any informal or mainstream supports.

We agree that this means that the NDIS will provide reasonable and necessary support that must be related to their goals and the things they want to do in their lives and help to improve their social and economic participation. This means also the cost of the support must be value for money and must not be something that people can be reasonably expected to provide for themselves .Also the support must not be one that is provided by other organisations.eg Centrelink , Medicare etc.

The Bill does not say how the Agency will decide which supports are reasonable and necessary or how it will work out what supports are not reasonable and necessary nor about the way in which the supports are to be funded. The Rules need to say about the kind of organisations that are allowed to provide the supports that are funded by NDIS.

- 3.2The Bill says that people can choose how their support plan can be managed such as they can choose their own support providers or they can choose to manage some or all of their funding themselves. Also they can ask someone-else to manage some or all of their funding. Also the Bill explains that there will be cases where it will be an unreasonable risk to a person to manage their own funding but the Bill does not say how this will be arrived at. Deaf people would want to know how this would come about.
- 3.3 The Bill recognises that there will be changes in peoples' circumstances and that people can request a review of their plan at any time or if a review of the plan can be suggested but there is no suggestion as to what might trigger a review or whether a person can change their plan without needing a review. There needs to be some detail given as to how this could be done.
- 4.1 The Bill says that the Agency will need to collect private information from people who want to be in the scheme and it is made clear when this is required. It is made clear that this information is protected and the law will punish those who reveal private information. The Agency may need to share this information with other Commonwealth or State Agencies but does not state what these circumstances are. Deaf people would want to know what those circumstances would be as they would regard their private information as protected.
- 4.2 The Bill says that "the Agency will work with the disability sector to make sure that services are of the standard and quality needed to best support people with disability" and that "any person or service which provides a support to that person must first be registered with the Agency." Any Plan Management Provider must also be registered.

The Agency does not spell out the qualifications needed to be a Provider.

- 4.3Children are not under our group of members.
- 4.4 The Bill recognises that some disabled people may need support in their decision making maybe by a relative or friend This person could be a "plan nominee" or "correspondence nominee". Their roles are set out in the Bill. This would need to be explained very carefully to the deaf or hearing-impaired person before they should agree to such a person and have their utmost trust. The Bill does not say what sort of person the Agency would accept in that role and how to make sure they are representing accurately what the deaf person wants and if the deaf person seems satisfied in the outcome.

Margaret Colebrook OAM Chairperson , Let Us Hear