The 2005

Libby Harricks

Memorial Oration

Honouring the Deafness Forum's first president & profoundly deaf achiever Elisabeth Ann Harricks AM 1945 – 1998

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Introduction to the 7th Libby Harricks Memorial Oration

Dr Jenny Rosen, Chairperson, Libby Harricks Memorial Oration Committee



As the first President of the then newly formed national peak body, Deafness Forum of Australia, Libby Harricks traversed the country working ceaselessly to raise community awareness, and to achieve equal access for people who are Deaf, hearing impaired, or have chronic disorders of the ear. After her death in 1998, the Libby Harricks Memorial Oration series was established in her honour, to continue her commitment to this cause.

In 1999 in Sydney, our inaugural Orator, Emeritus Professor
Di Yerbery, set a very high standard with her topic, 'Hearing access
now!' In 2000 at the International Federation of Hard of Hearing
Conference, also in Sydney, Professor Bill Gibson spoke on tinnitus
and Menieres Disease. In 2001, in Canberra, Senator Margaret Reid
spoke on 'The politics of deafness,' and in 2002 at the XXVI
International Congress of Audiology in Melbourne, Professor
Paul Mitchell presented findings of the Blue Mountains Hearing
Study. The 2003 Oration, regarding disability law and hearing loss,
was presented by Donna Sorkin as the keynote address to a full day
hearing access seminar held at Macquarie University, Sydney. As an
integral part of the 3rd National Deafness Summit in Brisbane,
in 2004 Dr Peter Carter gave us a summary of the present status
of Aboriginal ear health.

At this point then, we are satisfied that we have had some success in reaching across our wide land, across our area of interest, and with excellent speakers. For that I must also thank the hard working Libby Harricks Memorial Oration Committee and the supportive Deafness Forum national secretariat, without whom this Oration series would not happen. This year I would also like to acknowledge the Blue Mountains SHHH (Self Help for Hard of Hearing People) group, for their on-going achievements in following essentially the same awareness and access aims, and for their support and encouragement in helping us to reach into the Blue Mountains community on this occasion.



For this year, we are tackling yet another frontier, by moving out of the capital cities to reach further into the community. To assist us with this, we are indeed fortunate to have yet another outstanding Orator, Alex Jones.

Born and educated in the USA. Alex's first language is sign, his second, English. A graduate of New York University's Tisch School of the Arts, Alex has been a professional actor for 20 years. He was the first Deaf actor inaugurated into the prestigious Mickey Mouse Hall of Fame, Recruited to Australia by the Australian Theatre of the Deaf, Alex has now made Sydney his home. He has starred in Fireflies, and in All Saints. As well as continuing to add to his extensive theatre, TV and film credits, Alex has also developed communication and education skills training for Deaf and hearing students. Earlier this year, Alex was the Festival Director for the critically acclaimed Cultural Festival associated with the Deaflympics Games in Melbourne. This was a world first. He is presently very busily self-employed as Founding Director of TAJ Productions which provides strategic consulting and advisory services to fund managers and corporate clients, develops and delivers tailored executive education programs, and manages core entertainment assets He is also the Actor/Director of a K-6 school show. Heads UP!

Alex is very active in, and committed to, raising community awareness, and to achieving equal access for, Deaf and hearing impaired people, as well as others with varying disabilities. In his Oration, he shares his experiences with us, as well as a new context for considering disability. Alex considers these 'differences' not as disability, but as a challenge.

He has therefore chosen for his Oration the powerful title 'Deafness and disability transformed. An empowering personal context.'

I would encourage you all to think very carefully about Alex's message, and about how you can contribute by carrying it forward into your own community.

Thank you.

Deafness and Disability Transformed: An Empowering Personal Context

Delivered by Alex Jones



Libby Harricks

It is an enormous privilege to be invited here today to honour the legacy of Libby Harricks. I never met Libby. It was a year after I arrived in Australia and I was working as an actor with the Australian Theatre of the Deaf. My friends told me a "news reporter" died. It took me a while to realise that it was not a news reporter, but rather Libby Harricks. It was Libby's sign name given by the Deaf community because she has always held a conference microphone with her so that she could hear people more clearly. I remember the palpable sense of loss of almost all around me. Since then I have become increasingly aware of Libby's influence throughout the deaf Community. It is a great personal tragedy of mine that I did not get to meet the woman who is the reason we are all here.

By all accounts Libby was a phenomenal presence – a woman who made people take notice. When Libby lost her hearing in the 1970s, rather than limiting her options, it gave her renewed vigour. She interrupted people's lives – literally on loudspeaker – and by doing so, created the opportunity for change. Libby was a passionate advocate for the deaf and hearing impaired. She helped found the Hornsby Ku-ring-gai Hearing Impaired Association now, aptly known as "Self Help for Hard of Hearing People." Libby served as a Board member on the Australian Deafness Council and was the founding president of the Deafness Forum. She was also a board member of Australian Hearing Services and Disability Council of NSW. She was made a member of the Order of Australia in 1990 for her work on behalf of the hearing impaired community. She was behind the Disability Access project for the Sydney 2000 Olympics, which sadly she did not live to see – but which I did.

Libby was, and remains, empowering through the example she set in dealing with her deafness and her disability. It is apt that it is against this backdrop I will begin today's conversation: 'Deafness and Disability: An Empowering Personal Context'.



This is not going to be a traditional oration. Firstly, I am not making any noise. For many of you, this will be the first oration you have seen signed. For others, some of the themes may prove uncomfortable. It is not my intention to present a discrete body of scholarly merit. It is my intention that you be engaged in the topic and perhaps reconsider some of your own settled views.

Introduction

Deafness. Disability. American. They are all brands. When I tell you I am Deaf, Disabled or American – you already know stuff about me because of what those brands mean to you. I like to wear Diesel and D&G and Prada shoes – that tells you more. I never go out of the house without Gucci Envy on. I went to NYU. I swim and love avant garde theatre. I am now an Australian. Who is starting to get a pretty clear picture of me now?

Who already knows I could hold my own at a cocktail party? Who would actually want to talk to me at that party?

I am intellectually disabled.

I am physically disfigured.

I am deaf.

I am gay.

I am blind.

I am black.

You are confused.

Because all those labels mean something. To you.

Which were positive, which were negative? Which aroused suspicion, respect, fear, admiration, pity? Could you tell what the person sitting next to you thought as I went through my list? Was it the same or was it different?

Is there such a thing as a "group" or social context for these labels? Is it an opinion you created on your own or an opinion shaped by others' influence? If so, are our individual views dependent on others or do we have complete freedom?

What I will suggest in this address is that our individual views are bound by the accepted social context. A good analogy is that of 'taste' - having lived in Thailand for a year, I think nothing of vegetables and curry for breakfast - while in Australia you can presume with confidence that this will not even be an option available for selection.

The same social context that says "bacon and eggs for breakfast", with an individual choice on poached or scrambled also dictates "abled" as better than "disabled" and individual choice on how you "manage" the disability. "Hearing" is obviously better than "deaf", "seeing" better than "blind". The interesting discussion, as I was asked last year is reduced to whether it would be "better" to be deaf or to be blind?

So in a reality where there is an established social context that defines the parameters of disability, what role the personal context, and how can it be empowering?

Broadly, I will contend that there are 3 options when faced with a disempowering social context:

- 1. Acquiescence (suffer the eggs)
- 2. Opt-out (move to Thailand to escape the eggs)
- Engagement and interruption (make a point of bringing your own vegetables and curry, because you know the café won't have any)

Before discussing each of these in turn, I will first look at what the social context for deafness and disability is:

Definitions

The Oxford English Dictionary defines disability as 1. lack of ability (to do something); inability, incapacity or 2. an instance of lacking ability; a physical or mental condition (usually permanent) that limits a person's activities or senses, especially the ability to work and 3. incapacity recognised or created by the law; legal disgualification.

While accurate and apparently innocuous, the context for these definitions in society is far less so. The social context is illuminated by a Language Do's Don't as produced by the NSW Department of Ageing, Disability and Home Care. The document cautions that the term "people with disabilities" is to be avoided in favour of "persons with a disability" as all too often we assume that one disability implies others. All too commonly people are defined as their disability ("John is a quadriplegic") rather than as a person with a disability ("John has quadriplegia"). The prevalence of the words "suffers from", "victim of" or "confined by" in language is noted.

Nevertheless, while strictly disability means a lack of ability to do a particular thing – a person with quadriplegia lacks the ability to walk, a person with a hearing impairment lacks the ability to hear – all too often disability implies abnormal and defective. Not that long ago, being "disabled" meant being an outcast. In some parts of the world, if a disabled child was born, it was viewed that the child and the family were cursed. In Western countries children were labelled "handicapped" and sent away to institutions far away from public life. There were obscene medical and psychological experiments done on disabled children.

My deaf grandfather rarely signed in public because he did not want to draw attention to his deafness. It was enormously rebellious of my father to sign in public with my mother. My grandparents were mortified because they feared the public would see them as abnormal. Many older deaf families are still ashamed about signing in public. My parents' hands were whipped at school if they were caught signing. I was not allowed to use sign language during my first three years at school.

While we have come a long way from sterilisations and institutionalisation, it is useful to remember that it is from this context which our current construct has evolved in a relatively short time. I want to consider how it has evolved, what the benefits have been, and what future we can work towards.

What I will contend is that all disabled people are likely to experience all three stages of acquiescence, opting out and engagement and interruption at some points in their lives.

What I would like to debate is the benefits and risks of each.

Acquiescence

When my buttocks were first slapped in February 1974, Dr. Warren A. Ward mouthed to my mother, "It's a boy!" My very first "label"! A boy. I was born to deaf parents in America who use sign language but the question was "am I deaf"? There was no way of knowing – none of my 3 brothers were. Not until I was 2, when my mother saw me having a signing conversation with myself in front of the mirror did she suspect. This sort of behaviour is common among deaf children and certainly it rang the 'deaf bell'.

The next day my parents took me to my first audiology exam. There I was locked in a metallic room filled with holes and wires everywhere. Headphones stuck tightly onto my ears and suddenly strong monotonous sounds were blasting through my ears. All I wanted to do was to get out of that room and eat those lollies the audiologist said I could if I was a good boy during the exam. It was with utter relief that I remember munching the lollies while my parents scribbled down notes back and forth with the audiologist.

Tucking into a jawbreaker, my mother turned to me, with a look of what I am certain was deep concern and signed, "Alex, you are deaf — just like us. You are different to your brothers." My world turned upside down. Me? I am like my parents? This was just not possible. I didn't want to be like my parents, I wanted to be like my cool older brothers. But I couldn't be.

In hindsight, that was the first moment I remember acquiescing to a social context. My parents' context was that I was "like them" and "not like my brothers". From that day on, my life at home really was "me and my parents" on the one hand and "my brothers" on the other. I would never fit in with them. They would always be out to get me. They would never understand me. They would never care. I had to rely on my parents - which was very uncool. Looking back, I doubt that my parents even intended those consequences of that sentence - they were probably trying to explain it in a way I would understand - but on that day my universe became defined by the context that I would be unable to fit in with my brothers. This context surely supplied an identity. It definitely brought me closer to my parents. It abrogated quite a lot of responsibility on my part - "I was deaf, I didn't need to do maths or write English" and for me, also precipitated a context of victim-hood. It also didn't do much to alter the social context. I just accepted it, unquestioningly. I acquiesced.

So, when that stopped working for me, what were my options? Faced with the choice of being like my parents or not, like most kids, I would have opted not to. How do I do that? I could pretend that I was not like them.

Opting-out

For years my mother would tell her friends that I was deaf whereupon I would slap my mother's wrist and tell her that I was not deaf but "hard-of-hearing." It was my way to be more like my brothers and less like my parents. So in my adolescence, I walked around with pride saying I was "hard-of-hearing". If being hearing was the norm and perfect, I would be closer to perfection if I was "hard of hearing". Like, it was better to be closer to being "hearing". Like the so called "coloureds" of Apartheid South Africa whose own status increased with how white they were - or black they weren't - even within their own community.

If my disability was bad – I would be less disabled than everyone else. Perfectly logical. "Hi, I am Alex and I am "hard of hearing"." My strategy was to opt out of being deaf.

Until I got a whiff of total freedom. Deaf Pride, Capital – D. I wasn't disabled at ALL. I was part of a "linguistic minority" with a proud language and rich culture and history. Being capital–D Deaf actually has nothing to do with hearing at all. The capital–D Deaf community defined itself by a way of life in which hearing is *irrelevant*. My hearing brothers are capital–D Deaf because they appreciate the culture and language of Deafness, its storytelling, its community. If you have ever been at a function full of signing people, you will quickly appreciate what I mean. There will be people there who can hear and people who can't but hearing itself is irrelevant. What is relevant is using sign language. My parents would take me to Deaf bowling every Tuesday and Thursday nights during school year. They would go to the Deaf Club.

I went to a Deaf school affiliated with America's Deaf University, Gallaudet, in Washington DC. Dr. I King Jordan was the first newly elected Deaf President of the only Deaf university in America and I wept with the promise that "Deaf people can do anything except hear". And in that rarefied environment it is very seductive to think that not being able to hear is not a disability. Where no-one speaks, everyone signs (including the chemist on campus), where

there are visual flashing lights for bells, TTY public phones, it is hard to think why you would need to hear at all! If other people didn't insist on talking, I wouldn't have a disability.

Gallaudet is a hugely empowering and impressive institution that has trained and qualified countless deaf graduates in many different disciplines by using sign language as a means of academic discourse. Behind the walls of Gallaudet – deafness is no disability.

Flush from the success of Gallaudet, the New York Times reported last month of the move to establish a Deaf town called Laurent in South Dakota – a haven of self–expression and freedom for deaf people to celebrate their language and culture. My old classmate who is leading this project has said that "society isn't doing that great a job of integrating us" and that their deaf "children don't see role models in their lives". They are creating a town where everybody must use sign language including City Hall, the postman and the whole of the community.

My experience of the Capital-D Deaf Movement is that there were two very significant costs. First, it only works as long as you manage to avoid the rest of the world – or you get them all to learn sign-language and stop talking. Hardly conducive to freedom and self-expression – and not really something I want to spend my life doing. A director of the Alexander Graham Bell Association of the Deaf and Hard of Hearing said, "I understand the desire to be around people like ourselves, and I don't have a problem with that, but I don't think it is very wise. This is a little bit of circling-the-wagons mentality". Secondly, and more fundamentally, it is a sell-out.

It sells out on our disability. There is a big movement of deaf people who utterly resist the notion that they have a disability. Why should we be lumped with all those people with real handicaps? I just can't hear. I have a perfectly "normal" brain, "normal" athletic prowess. You can't even tell just by looking at me.

Deaf people do not participate in the Paralympics - we have our own Deaflympics. While some argue this is because of the unique communication modes of deaf team sport, the reality is that many deaf people do not want to go near the subject of disability.

Is selling-out such a bad thing? Aside from the morality of selling out on other people with a disability, taking this opt-out to its

logical conclusion would deny deaf people the benefits of the Disability Discrimination Act. What about the rights of deaf people to access a job, education and services? As if they did not have that disability, they are not entitled to these rights. Is this what we want?

Treating deaf people like a "linguistic minority" equates us with immigrants who cannot speak the language. This hides a very real difference. Immigrants can learn the language and get full access. We are not able to do so. No matter how much schooling I have, I could not watch the TV news without captions and understand it. I could not have gone to university to study theatre without interpreters. I can't hear. I don't have that ability. I have a disability. That is reality.

But does opting-out alter the social context?

While unquestionably, it catapulted possibilities for deaf people a huge way, Capital–D Deafness worked largely on the social context it directly affected – which by its very nature was limited to the Capital–D Deaf people who embraced it. Its impact on the rest of society was necessarily limited – in a direct sense to a few news reports, human interest stories, and isolated interactions. Perhaps its greatest impact is that of those people who have experienced its affirming identity and venture out into the real world.

Which brings me to the third strategy. Engagement and interruption. Libby and her microphone. You had to take notice.

Engagement and interruption

Faced with a social context that is disempowering, one has the option of challenging it head on. To do so requires engaging with it and being an interruption to accepted norms. Libby was exactly that.

By engagement I mean confronting and dealing with the reality of the situation, of the discrimination, of the assumptions. By interruption I mean interrupt the accepted social construct to make way for a new possibility.

Recent changes to captioning laws have only occurred because disabled people have no longer accepted that we should take a back seat, that we should be grateful for the little we get, that we should not "push our luck".

Engagement and interruption need not be confrontational. Sometimes it can be as simple as demystifying the disability and humanising the disabled person (or consumer). Having worked closely with the Subscription Television industry for the last two years, I want to acknowledge the enormous shift that has occurred there. The dominant paradigm of "we don't want to provide captions because they are costly" was interrupted and through engagement with the community I believe we are now at a place where the industry is asking "how best can I serve my deaf subscribers?" An industry that promised a minimum of 5% captioning this year is set to massively exceed this guarantee in its first year of captioning with very high quality standards.

The benefit of engagement and interruption is that it tackles the root cause of the struggle many of us with a disability face every day. It provides the opportunity to present a counter-view to the negativity of living with a disability.

When people used to tell me I was an inspiration, I would often think they were being condescending. But the reality is that a person with a disability, going about every day life does present others with possibility and hope. Everyone gets dragged down by the mundaneness of life and its stresses. Getting past "a real disability" to enjoy life is inspiring for many.



Deafness and Disability Transformed: An empowering personal context

Finally, I want to give you a counter-view on deafness and disability. An empowering personal context that centres on opportunity and ability. We actually have the opportunity to inspire others to a degree that "normal" people cannot. A personal context that provides a great cornerstone for an emerging social context.

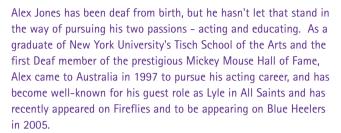
I would not have the privilege of standing here today if I was not disabled. I would not be able to perform my school show. I would not have the opportunity to interrupt and make a difference to the lives of resigned and cynical school children around the country. I would not have had the opportunity to produce the Cultural Festival for the Deaflympics Games. I certainly would not have been signing the weather on Channel 10 news or on Sunrise and probably would not have been on All Saints or Blue Heelers. I would not have launched captions on FOXTEL last year. I also, would not have nearly the visual communication skills that I have. I wouldn't actually be me.

Last year, the Department of Ageing, Disability and Home Care asked me to be one of the ambassadors for the International Day of People with a Disability. The theme being "Don't DIS by Ability". My disability has given me a life I could never have had without it. I am proud of what I have achieved and yes, I am proud to be a disabled person who is deaf. It was a great honour to share the stage with other ambassadors for the International Day of People with Disability. The sense I was left with was that being disabled does not strip anything away from who you are – it adds flavour.

My answer to the question of whether I would prefer to be deaf or blind was to say that I would rather be deaf than hearing. It caused a stir at the time – but if I wasn't deaf, I wouldn't be me!

Remember Libby's legacy – she embraced her own disability and made a difference in the lives of others. The challenge for us in the years ahead is to continue to create empowerment around disability, to continue to use technology to overcome what the disability prevents being done and focus on freeing and celebrating the human spirit of every individual. Who wants to be normal, anyway?

Bio on Alex Jones



Alex combines his acting career with work in business and as an educator. As a founding director of TAJ Productions, he is an integral part of Heads UP!, Heads UP! ACTIVE and Heads UP! HIGH, an exciting and innovative school theatre production that brings hearing and Deaf culture together for Australian school children (both Deaf and hearing).

Alex was festival director of the first ever Deaflympic Games Cultural Festival in January 2005. The festival celebrated the talents of Deaf artists from all over the world in theatre, dance, mime, cabaret, comedy, film and children's entertainment while also celebrating international deaf culture.

Alex helped launch closed captioning on the subscription TV platforms in October 2004. TAJ Productions assisted FOXTEL and ASTRA (Australian Subscription TV & Radio Association) to develop a roll-out plan for closed captioning on Subscription TV in Australia in consultation with peak national Deaf and hearing impaired interest groups and the Human Rights and Equal Opportunity Commission. Alex served as an ambassador for the International Day of People with Disability in NSW in 2004.

More information on Alex Jones and TAJ Productions can be found at www.tajproductions.com.au.





The Libby Harricks Memorial Oration program is supported by the Libby Harricks Memorial Fund of the Deafness Forum of Australia. Donations to this fund are tax deductible. Please see enclosed donation form for full details.

Donations should be made payable to Deafness Forum. Additional donation forms and general information regarding deafness can be obtained from:

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Libby's Story



Libby's story is one of courage and triumph over adversity by utilising the knowledge of her own severe hearing loss to help others.

Libby started to lose her hearing following a bad dose of flu in the English winter soon after her marriage in 1969. Having returned to Australia in 1970 she began to find difficulty in understanding conversation and instructions, particularly on the telephone which was very important in her profession of pharmacy.

In spite of advice to the contrary, Libby tried hearing aids and found they helped. Had she heeded the negative advice, Libby believed she might never have embarked on the road to self-help, which so enriched her own life and that of many others.

She thought her two boys quickly learnt to sleep through the night and her friends remarked they had loud voices, which was the boys' mechanism for coping with a deaf mother!

The more the doctors said nothing could be done to help, the more Libby looked towards self help and so she learnt to lip read, a tool she relied on heavily in her quest to help others.

Libby's will to win led her, with the help of others, to get involved with the setting up of a support group, which became SHHH – Self Help for Hard of Hearing people. The American founder, Rocky Stone, was invited to Australia in 1982 and did a lecture tour entitled "The Hurt That Does Not Show" which cemented the bonds between the US and Australian groups and helped the local SHHH develop.

Libby, with others, then began SHHH News, a quarterly publication, and with Bill Taylor set up the first Hearing Information and Resource Centre at "Hillview", Turramurra with support from Hornsby/Kuringai Hospital. This centre provided reliable information on, and demonstrated, assistive listening devices for hearing impaired people. Through this interest, Libby became an enthusiastic user of technology and with her handbag full of electronic aids was enabled to join in a full social life with family and public.



Libby became President of SHHH in 1986 and began to develop her role as an advocate for hearing impaired people generally. She became involved in ACCESS 2000, under the Australian Deafness Council, and a member of the Disability Council of NSW. Her horizons broadened further as Vice President of the Australian Deafness Council and then as the first, and two terms, President of the newly formed national peak body in deafness, the Deafness Forum of Australia. In this latter role Libby made a huge contribution to bring together all the different organisations into a central body, and actively lobbied on behalf of Deaf and hearing impaired at the highest level – the archetype of a successful achiever despite her profound hearing loss.

For her work on behalf of hearing impaired people Libby was made a Member of the Order of Australia in 1990. Later she was appointed by the Government to the Board of Australian Hearing Services and was asked to represent the needs of hearing impaired on the Olympic Access Committee.

Unfortunately, Libby faced another hurdle when she was diagnosed with breast cancer in 1995. Following surgery, she continued her family and volunteer work with undiminished vigour. She would wickedly show off her wig at public functions after her chemotherapy, and talked openly of her "mean disease". She died peacefully on 1 August 1998 and was honoured by hundreds who attended her Thanksgiving Service on 6 August.

In her own words, Libby related her outlook:

"I look back over these years since I became hearing impaired and realise that any efforts that I have made have been returned to me threefold. I have found talents I never knew I had, I have gained so much from the many people I have met and worked with to improve life for people with disabilities and through self help I have turned the potential negative of a profound hearing loss into a positive sense of purpose and direction in my life".



Introduction

Deafness Forum is the peak body for deafness in Australia. Established in early 1993 at the instigation of the Federal government, the Deafness Forum now represents all interests and viewpoints of the Deaf and hearing impaired communities of Australia (including those people who have a chronic disorder of the ear and those who are DeafBlind).

Structure

The representational base of the Deafness Forum is divided into five Sections:

- Hearing Impaired Section persons with a hearing loss who communicate predominantly orally,
- b) Deaf Section i.e. the Deaf Community those persons who consider themselves to be members of that community by virtue of its language (sign language known as Auslan) and culture,
- Ear Disorders Section persons with a chronic ear disorder (such as Tinnitus, Meniere's Disease or Acoustic Neuroma) and
- d) Parents section parents or legal guardians of persons who are Deaf or hearing impaired,
- e) Service Providers section service providers to the Deaf and/or hearing impaired communities.



Objectives

The Deafness Forum exists to improve the quality of life for Australians who are Deaf, have a hearing impairment or have a chronic disorder of the ear by:

- · advocating for government policy change and development
- · making input into policy and legislation
- generating public awareness
- providing a forum for information sharing and
- creating better understanding between all areas of deafness.

Community Involvement

The Deafness Forum is consumer-driven and represents the interests and concerns of the entire deafness sector, including:

- the Deaf community
- people who have a hearing impairment
- people who have a chronic ear disorder
- the DeafBlind community
- parents who have Deaf or hearing impaired children in their families

Notes





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